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A PROFILE OF MEDICAID HOME AND COMMUNITY-BASED CARE WAIVERS, 1985: FINDINGS OF A NATIONAL SURVEY

Susan S. Laudicina
Brian Burwell

Contract No. 500-83-0056

Department of Health and Human Services
Health Care Financing Administration
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This monograph is one in a series of studies undertaken as part of the La Jolla Management Corporation national evaluation of Medicaid Section 2176 Home and Community-Based Care Waivers. SysteMetrics/McGraw-Hill, Inc. provided subcontractor assistance.

The statements contained in this report are solely those of the authors and do not necessarily reflect the views or policies of the Health Care Financing Administration.

PREFACE

The Medicaid program, which finances health care for over 20 million needy Americans, has undergone major changes since 1981. Beginning with the Omnibus Budget Reconciliation Act of 1981 (OBRA), Congress gave the States much more flexibility to change basic parameters of the program, including which groups of people are served, which services are provided, how doctors, hospitals and nursing homes are paid, and how care can be organized in innovative ways.

The Medicaid Program Evaluation addresses the implementation and impact of selected changes in the Medicaid program to provide knowledge for policy assessment and future legislative change. It is focused on selected issues and policy questions raised by recent legislation. The three-year evaluation included nine major study areas:

- Federal Financial Participation
- Inpatient Hospital Reimbursement
- Eligibility
- Case Management
- Home and Community-Based Waiver Program
- Cost-Sharing
- Financial Incentives for Family Care
- Medicare PPS Effects on Medicaid and
- Synthesis.

Together these studies are intended to describe how recent changes have been implemented and analyze what their effects have been for program services and costs.

This report presents the findings of a national survey of the Medicaid home and community-based care waiver programs established under Section 2176 of OBRA. It highlights the results in terms of geographic coverage of the waiver programs, enrollment levels, client screening techniques, client characteristics, service utilization, expenditures and quality assurance. States generally depicted their waiver programs as of September 30, 1985.

Gerald S. Adler
Project Officer
Medicaid Program Evaluation

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EXECUTIVE SUMMARY

This report presents the findings of a national survey of Medicaid home and community-based care waiver programs established under Section 2176 of the Omnibus Budget Reconciliation Act of 1981. It highlights the results in terms of geographic coverage of the waiver programs, enrollment levels, client screening techniques, client characteristics, service utilization, expenditures and quality assurance. States generally depicted their waiver programs as of September 30, 1985.

HOW HAVE STATES USED THEIR WAIVERS?

- In Federal FY 1985, forty-two States were providing a broad array of health and social services under 75 regular waiver programs. Thirty-four of these programs served the aged and/or physically disabled (A/D); 35 served the developmentally disabled and/or chronically mentally ill (DD/CMI); and 6 combined programs served both population groups (A/D-DD).

- All waiver programs combined had a cumulative enrollment of 124,260 persons from their implementation date through September 30, 1985. Nearly three times as many aged/disabled persons have participated than clients characterized by developmental disabilities/ mental illness.

- The growth of Section 2176 waiver programs since 1981 has been marked. A/D recipients of waiver services have increased from 6,389 in 1982 to 45,934 in 1984. During the same period, DD/CMI recipients have grown from 10,253 to 21,823.

- The total active caseload of all waiver programs as of September 30, 1985 was 70,037, distributed as follows: A/D clients - 47,819; DD clients- 21,109; and CMI clients - 1,109.

- DD waiver programs have significantly higher program penetration rates into the DD Medicaid long-term care population than do A/D waivers into the comparable A/D Medicaid long-term care population. ("Penetration rates" are defined as the ratio of waiver recipients to institutional residents plus waiver recipients.) In 1985 the overall penetration rate for DD waivers nationwide was 23.0 percent, and ranged from 2.7 percent to 68.4 percent in individual states. This contrasts markedly with the A/D programs, which experienced an overall penetration rate of 3.0 percent, and ranged from less than 1 percent to 15.5 percent.

- The size of current waiver programs varies widely among the States. Florida and Illinois have the largest A/D waiver programs, with 7,507 and 5,928 enrollees, respectively. The States with the largest DD/CMI caseloads were Florida with 6,979 and California with 3,069. Five States (California, Florida, Illinois, New York and Oregon) represent 56 percent of the national A/D caseload; while, five (Alabama, California, Colorado, Florida and New Jersey) account for 66 percent of the DD/CMI caseload. The national averages are 1,195 clients per A/D waiver and 542 per DD/CMI waiver.

- The lead agency for A/D programs is usually the State Medicaid agency; the entity most often reported as directing the DD/CMI programs is the State Mental Retardation/Developmental Services agency. However, responsibility for the waiver programs is frequently delegated by the lead agencies, so that a majority of the time an entity other than the lead agency is the one reimbursed for waiver administrative services and/or the agency employing waiver case managers.

HOW DO INDIVIDUALS GET INTO THE WAIVER?

- There are three major client groups eligible for services under the waiver: (1) the aged and/or physically disabled, most often defined by States as over 65 years of age; (2) the developmentally disabled or mentally retarded of all ages; and (3) the chronically mentally ill of all ages.

- In addition to these categories, States have defined Medicaid waiver eligibility in terms of other eligibility options. In 44 waiver programs, States have chosen to exclude the income of parents or a spouse in determining eligibility; and 46 programs deny waiver services if they would be more costly than institutional services. In 29 waiver programs, States have elected to serve individuals qualifying as medically needy in addition to those qualifying as categorically needy.

- Federal regulations stipulate that waiver recipients be must medically eligible for nursing home admission. However, only half of the A/D waiver programs link waiver eligibility to mandatory pre-admission screening of nursing home applicants. Most DD/CMI waiver programs do not apply targeting criteria above and beyond the ICF-MR criteria required by Federal regulations.

- The A/D waiver programs have not deinstitutionalized a significant number of patients. The great majority of waiver recipients, some 83 percent, were living in a private residence when they entered the waiver; only 2.4 percent were in a nursing home. In contrast, while most States do not limit DD/CMI waiver admissions to deinstitutionalized clients, many do give priority to such persons in allocating waiver program slots. In FY 1985 one-third of all DD/CMI waiver clients entered the program from an ICF-MR or other institutional setting.

WHAT ARE THE CHARACTERISTICS OF WAIVER RECIPIENTS AND WHAT SERVICES DID THEY RECEIVE?

- Aged and disabled waiver recipients are an elderly, frail group in need of personal assistance. Four-fifths of all clients were 65 years of age or older; one-fifth were over 85. This population is overwhelmingly female (75 percent) and single (81 percent). A/D clients are characterized by a significant degree of impairment in their ability to carry out basic self-help activities, as measured by an Activities of Daily Living (ADL) scale. Fifty-one percent required assistance in toileting and/or eating, while 44 percent needed help in bathing and/or dressing.

- Except for the fact that they are less likely to suffer from mental disorders and more likely to live in poverty, A/D waiver recipients are largely indistinguishable from nursing home residents across a wide range of variables.

- The following three types of services are the backbone of the A/D waiver programs: "Case Management" (used by 54 percent of clients), "Personal Care" (used by 31 percent) and "Homemaker" (used by 21 percent).

- In contrast to the A/D waiver population, most DD/CMI waiver clients are young adults, between the ages of 22 and 39. Fifty-five percent are male.

- DD waiver recipients are generally less disabled than ICF-MR recipients. Mildly and moderately retarded persons comprised 25 percent of the ICF-MR population, but 53 percent of the waiver population. Profoundly retarded persons comprised 50 percent of the ICF-MR population, but only 17 percent of the waiver population. However, there is also considerable overlap between the two groups.

- The three most common types of services used by DD/CMI clients are: Case Management (92 percent), Habilitation (71 percent), and Residential Services (40 percent).

HOW MUCH IS SPENT ON THE WAIVERS?

- Total waiver expenditures nationwide reached $257,289,124 in Federal FY 1985.

- Thirty-seven percent of waiver expenditures, or a total of $96,015,448, was spent by all A/D waiver programs combined in FY 1985. Spending on personal care together with homemaker services (which overlap with personal care in most State service definitions) accounted for approximately 55 percent of all A/D waiver expenditures.

- Although the majority of waiver clients are A/D (68 percent as of September 30, 1985), most waiver expenditures (63 percent) are for DD/CMI clients. Some $161,273,676 was spent by all DD/CMI waivers in FY 1985.

Almost 80 percent of all DD/CMI waiver expenditures went to pay for Residential Services and Habilitation.

- In FY 1985 the average cost per recipient of DD/CMI services was considerably higher than the average A/D cost per recipient, some $7,259 compared to $2,008.

- The average Medicaid cost per day of waiver coverage for A/D clients in FY 1985 was significantly lower than the average Medicaid cost per nursing home day: $16.28 compared to $41.96. While costs for DD/CMI waiver clients are higher, they are considerably lower than the average ICF-MR daily cost: $45.05 per day for treating DD/CMI clients in the waiver as compared to $93.84 for a day of ICF-MR care.

- While the survey found no evidence that the A/D programs have played a major role in reducing the number of nursing home beds, this is not the case with the DD/CMI waivers. Twelve States indicated that the DD/CMI waiver had a direct impact on reducing the number of beds in public ICF-MRs; four States reported that public ICF-MRs had been closed altogether as a result of the waiver; and ten States said that the development of new beds in public ICF-MRs had been diverted due to the waiver program.

WHAT IS THE QUALITY OF WAIVER SERVICES?

- Although the survey asked States to describe the procedures which they have established to monitor the quality of care provided to waiver recipients, it is not possible to judge from survey data how well States are actually performing quality review. What the survey does make clear, however, is that States generally report a higher level of effort in monitoring the quality of care received by waiver clients as compared to the Medicaid population at large.

- One of the significant responsibilities of case managers in A/D programs is to perform quality assurance activities. These include, in particular, monitoring the quality of care provided to waiver clients and performing periodic level of care redeterminations.

- Two-thirds of A/D programs perform periodic independent review to determine if care plans continue to meet client needs, and if clients actually receive the services in the care plan. (By "independent review" is meant independent of the provider or case manager.) One-third of the programs indicate that they directly observe the care provided and/or assess client outcome.

- In most DD/CMI waiver programs, multi-level quality assurance mechanisms are used to monitor the care provided to waiver clients. In two-thirds of the programs, an independent review of the care plan is conducted. In virtually all programs, providers are monitored to ensure that care plans are properly implemented, and this includes the direct observation of clients by an independent monitor. In nearly all DD/CMI programs monitors compared

actual client outcomes with the treatment objectives specified in the care plan to determine the degree of client progress toward their goals.

CONCLUSIONS

The rapid growth in waiver enrollment from the program's inception in 1981, and the existence of numerous programs in all regions of the country suggest that States find the coverage of home and community-based services under Medicaid a highly attractive service option. A broad variety of State administrative structures have emerged in response to the Section 2176 waiver authority. Shared managerial responsibility among two or more entities is the norm. Some States have indicated that such organizational fragmentation increases the difficulty of administering waiver programs and hinders record keeping efforts.

States employ numerous formal screening criteria in an effort to direct waiver services to individuals who, but for the waiver, would need to be institutionalized. However, more accurate identification of the population at-risk of entering a nursing home might be achieved by greater emphasis on deinstitutionalization of patients and by linking the waiver assessment process with mandatory pre-admission screening of nursing home applicants. Some A/D waivers screen applicants based solely on nursing home level of care criteria. This simplistic approach to targeting waiver eligibility may result in making waiver services available to people who are not necessarily nursing home bound. In most States, the majority of developmentally disabled persons who qualify for Supplemental Security Income assistance could also meet ICF-MR level of care criteria. Therefore, many mentally retarded persons who have never been institutionalized and are at low risk of entering an institution could meet the targeting criteria for entry to the waiver program.

The A/D waiver population is generally quite similar to the nursing home population in terms of most demographic and functional characteristics. Data on the characteristics of DD waiver recipients and ICF-MR recipients suggest that the waiver population is, on average, not as impaired as the ICF-MR population. This does not necessarily mean that DD waiver programs are not substituting for ICF-MR

care, because one would expect a program to focus on relatively higher-functioning clients for whom ICF-MR care is not the most cost-effective care setting.

While survey findings do not allow any conclusions to be drawn concerning the cost-effectiveness of waiver expenditures per se, some observations are indicated. The cost to Medicaid of treating the average person in a waiver program is significantly lower than the average cost of a nursing home day or day of ICF-MR care in the same State. However, the lower reported daily costs of waiver care as compared to nursing home care do not necessarily translate directly into savings for the Medicaid program. This is because when a Medicaid recipient receives a waiver day of care it does not automatically mean that a nursing home day will be avoided. In those States where there is a nursing home waiting list, the vacated bed could be filled by a different Medicaid recipient, with the result that Medicaid would end up paying for a nursing home bed in addition to waiver services. On the other hand, if the waiver program has the effect of shortening nursing home waiting lists, it could result in cost avoidance to the Medicaid program if fewer beds need to be built in future years.

The relative cost of a day of waiver care and a day of institutional care in a State can be translated into a break-even ratio for a waiver program. As reported on the survey, State waiver programs exhibit a wide variation in cost per waiver day of care. The fact that some States have lower costs is important because lower cost per waiver day implies that a lower degree of accuracy in screening applicants will be needed in order for a waiver program to break-even. That is to say, the lower the screening effectiveness rate required, the greater the likelihood that a particular waiver program will be budget neutral to Medicaid.

The cost of treating DD/CMI waiver clients is significantly higher than the corresponding costs for A/D waiver clients. At the same time, since DD waiver programs generally have higher penetration rates than do their A/D counterparts, it is more reasonable to expect measurable impacts of DD waiver programs on utilization of and expenditures for ICF-MR care, than it is to expect measurable impacts on utilization of and expenditures for SNF and ICF care by Medicaid recipients.

Quality assurance is a high priority for most waiver programs. States are sensitive to the fact that waiver clients are vulnerable and need systematic attention. States report more intense monitoring of waiver clients than that typically provided for the Medicaid population at large. In evaluating Section 2176 waivers, it is important to keep in mind that the cost impacts of the program, positive or negative, must be qualified by information on the quality of waiver services compared to the care provided in institutional settings in order to arrive at a true assessment of a waiver's success or failure.

CHAPTER ONE
BACKGROUND AND PURPOSE

The evaluation of the Section 2176 Medicaid home and community-based care waiver is a component of an overall HCFA evaluation of recent legislative changes to Medicaid. This report presents the findings of a national survey of all Medicaid home and community-based care programs conducted under the authority of the Section 2176 waiver.

BACKGROUND

Under Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), States are allowed, with the approval of the Secretary, to provide a variety of home or community-based services to certain individuals who would otherwise require nursing home placement. This waiver authority signals a major change in Federal Medicaid long-term care policies, which previously had emphasized medical services delivered in an institutional setting. States have the ability to serve any or all of the following groups under their waiver programs: the elderly, the physically disabled, the developmentally disabled and the mentally ill.

The objective of Section 2176 is to prevent or delay treatment in nursing homes by substituting less costly home and community-based services where appropriate. In an attempt to control costs, the statute requires that States provide assurances that per capita Medicaid expenditures for the relevant population group will not increase as a result of the waiver. Moreover, in implementing this provision, HCFA developed a cost formula to be completed by States applying for waivers which also requires that aggregate Medicaid program expenditures not increase with the waiver. Since reimbursements to nursing homes comprise over 40 percent of the total Medicaid budget or some $16.5 billion in Federal fiscal year 1985, decision-makers at both the Federal and State levels are interested in the impact of the Section 2176 program on the traditional health care delivery system financed by Medicaid.

Before enactment of Section 2176, non-medical services had generally not been eligible for reimbursement under Medicaid. Under the new law, any or all of the following home and community-based services may be furnished:

- Case management
- Homemaker
- Home health aide
- Personal care
- Adult day health
- Habilitation
- Respite care
- Other services requested by the State Medicaid agency and approved by HCFA as cost-effective and necessary to prevent institutionalization.

Waivers are granted to States for a three-year period. They are reviewed annually, and currently may be renewed for an additional three years. Beginning September 30, 1986, the renewal period will be extended to five years. This is one of several changes to Section 2176 that has been mandated by the Consolidated Omnibus Budget Reconciliation Act of 1985.

There is no limit to the number of waivers a State may request. As of April 21, 1986, 47 States had submitted a total of 182 regular waiver requests under Section 2176, of which 105 had been approved and 29 were pending; the remaining 48 had either been disapproved or withdrawn.

The Section 2176 waiver allows the States flexibility in designing their programs in several important respects. For example, States may choose not to offer the program statewide, as they are normally required to do in the Medicaid program. States may also offer a different mix of services to different target groups. They can also be permitted to deny services to clients for whom community-based care would be more costly than institutional care.

PURPOSE OF THIS REPORT

This report is part of the HCFA evaluation of the Section 2176 waiver authority. The evaluation is a four-year effort with the following major objectives:

- To determine the manner in which States have used their waiver authority
- To ascertain whether waivers have been targeted to people at high risk of entering nursing homes
- To explore whether the waiver program is a cost-effective alternative to institutional care
- To examine the quality of waiver services, and to assess their impact on patient outcomes
- To describe the characteristics of successful waiver program designs.

The evaluation is collecting data on the Section 2176 waiver programs from several complementary sources, including:

- annual surveys of waiver programs nationwide,
- State reports to HCFA,
- national expenditure data, and
- selected State-level case studies.

The results of the first year of the evaluation were largely descriptive in nature and were published in a Report to Congress entitled: Studies Evaluating Medicaid Home and Community-Based Waivers (HCFA, 1984). A second national survey on the detailed operations of all State waiver programs was conducted in January of 1986 and is the basis for this report. In addition, the following project reports have been prepared during the second year and third years of the evaluation: an analysis of waiver program impacts based on State reports to HCFA; and analysis of overall trends in Medicaid nursing home utilization and expenditures nationwide; and four separate case studies of waiver programs at the State level. The results of the seven project monographs form the substantive basis for the interim evaluation report (La Jolla Management Corporation, Evaluation of Medicaid Section 2176 Home and Community Care Waivers, 1986). The interim evaluation report contains an

update of the waiver programs generally, as well as preliminary evaluation findings. The final report of the evaluation scheduled for December, 1987 will again update the waiver programs, present additional case studies, and derive conclusions and suggestions regarding the major evaluation objectives.

The present report addresses each of the five major evaluation objectives set forth above on the basis of a survey of State waiver programs conducted in January, 1986. Through the use of survey data generated by the States themselves, it documents how States used their waiver authority; how States attempted to target their programs to people at-risk of institutionalization; and what quality assurance systems have been established. In addition, it offers preliminary observations on whether the waiver program is cost-effective; and what some of the attributes of a successful waiver program are.

METHODS AND DATA

The survey of waiver programs was conducted in order to obtain information essential to the evaluation of Section 2176. This was necessary for several reasons: (1) although HCFA maintains administrative records on each waiver, there was no comprehensive data source on waiver program characteristics that corresponded to a uniform time period; (2) Vital research data such as waiver client functional dependency and primary medical diagnosis were not available from any existing source; and (3) Data on waiver expenditures based on the date of service delivery (rather than payment) was lacking.

The major subject areas addressed in the questionnaires were waiver program administration, geographic coverage, enrollment levels, screening and assessment, client characteristics, service utilization, expenditures, and quality assurance activities. The surveys also asked States to indicate areas where they felt waiver program administration and regulation could be improved.

Separate survey instruments were prepared for the waiver programs serving the Aged/Physically Disabled and the Developmentally Disabled/Chronically Mentally Ill populations. Although generally similar, the surveys do contain several questions tailored to each type of waiver in order to more accurately assess the programs in

light of the different characteristics of the clients being served. The survey instruments have been specifically designed to complement data which would be available from other sources. Both the A/D and DD/CMI instruments appear in the Appendices.

The surveys were mailed to all States which had active waiver programs at some point during the study year of October 1, 1984 through September 30, 1985. A telephone follow-up was conducted with primary respondents to the questionnaires in order to complete any missing responses and to verify the data submitted. A total of 75 surveys were sent to 42 States participating in the Section 2176 waiver. These included 34 waiver programs serving the Aged/Physically Disabled, 35 programs serving the Developmentally Disabled/Chronically Mentally Ill and 6 programs serving combined populations.

The survey response rate was 100 percent, i.e., every State filled out and returned its questionnaire(s). However, actual survey completion rates varied depending upon the substantive section or individual question involved. The following sections experienced the highest completion rates and usable entries for both A/D and DD/CMI waiver programs: "Program Overview," "Other Waiver Provisions," and "Screening/Assessment/Intake." Nearly every question in these sections of the surveys received a response rate of 85 percent or higher. The next group experienced response rates almost as high, with a 70 percent or higher completion rate for nearly every question: "Service Utilization and Expenditures," "Health Care System Developments," "Quality Assurance," and "Waiver Management Issues."

State respondents did indicate some difficulty in answering questions concerning some other aspects of the waiver programs, however. In the section dealing with "Enrollment/Disenrollment" of waiver recipients, the completion rate was 60-65 percent for questions dealing with the number of waiver applicants assessed; where waiver clients come from; and the reasons for eventual discharge. The gaps in data collection were more significant for the section "Characteristics of Waiver Program Population." The completion rate for questions in this section ranged from 43 to 65 percent for both A/D and DD/CMI programs. At the time the survey was conducted, a number of States had insufficient data on which to answer questions

concerning the age and sex of waiver recipients, their functional levels, and their primary diagnoses. However, the usable sample size was sufficiently large to infer a profile of waiver client characteristics.

The data collected by the surveys can, in some cases, be classified as either "actual" or "estimated." This choice arose in approximately 20 percent of the questions addressed to States. Generally speaking, States relied on actual data at least half of the time in responding to questions dealing with enrollment levels; caseload size; lengths of waiver enrollment; and reasons for discharge from the program. In contrast, most State respondents utilized estimated data in completing questions dealing with points of entry into the waiver; reasons for denial of waiver applications; and demographic and functional characteristics of waiver recipients.

In summary, the information contained in this report is accurate to the best of the contractor's knowledge. Most of the survey questions and all of the important variables have been verified through the following means: (1) Phone checks with State officials to follow up missing or suspicious entries; (2) Numerous automated edit checks on reported figures to determine their consistency and credibility; and (3) Spot checks on routine coding of responses as performed by data entry operators.

ORGANIZATION OF THIS REPORT

Chapter Two of this report contains a profile of how States have responded to the increased program flexibility made possible by Section 2176. It provides a comprehensive overview of what home and community care programs are available, who receives these services, how much they cost, and how they are managed and who pays for them.

Chapter Three examines several key variables which characterize the programs designed to serve the aged and physically disabled populations. It first analyzes how waiver applicants are screened for admission to the programs, and how the States define the population "at-risk" of institutionalization. Then the demographic and functional characteristics of individuals admitted to the waiver programs are set forth in detail. The next section explores the types of services and the cost of

care provided to waiver clients. Chapter Three also examines the impact of the waiver programs on nursing home utilization, and their relationship to informal care provided by family and friends. Finally, the chapter describes how home and community-based services provided under Section 2176 are being monitored by the States, and what types of quality reviews are performed.

Chapter Four analyzes the same set of variables for those waiver programs serving developmentally disabled and/or chronically mentally ill persons. Chapter Five describes the experience with Section 2176 from the point of view of the State agencies which administer the waiver programs. It provides the States' perspective on what have been the most problematic aspects of the waiver programs in practice, as well as their suggestions for future changes in the program.

Appendix A and Appendix B contain the survey instruments which were employed in collecting data on Section 2176 waiver programs.

CHAPTER TWO
STATUS OF WAIVER PROGRAM IMPLEMENTATION

The La Jolla Waiver Survey was designed to capture data along two timeframes: (1) the cumulative experience of each waiver program from its inception through September 30, 1985; and (2) the key characteristics of each approved program during the selected study year of October 1, 1984 through September 30, 1985.

SERVICE POPULATION

The survey reveals an intense level of interest among States in all regions of the country in participating in the Section 2176 program. Exhibits 2-1 and 2-2 provide at a glance the geographic distribution of approved State waiver programs as of September 30, 1985. About half of all States participating in the program operate more than just one waiver and are serving multiple population groups.

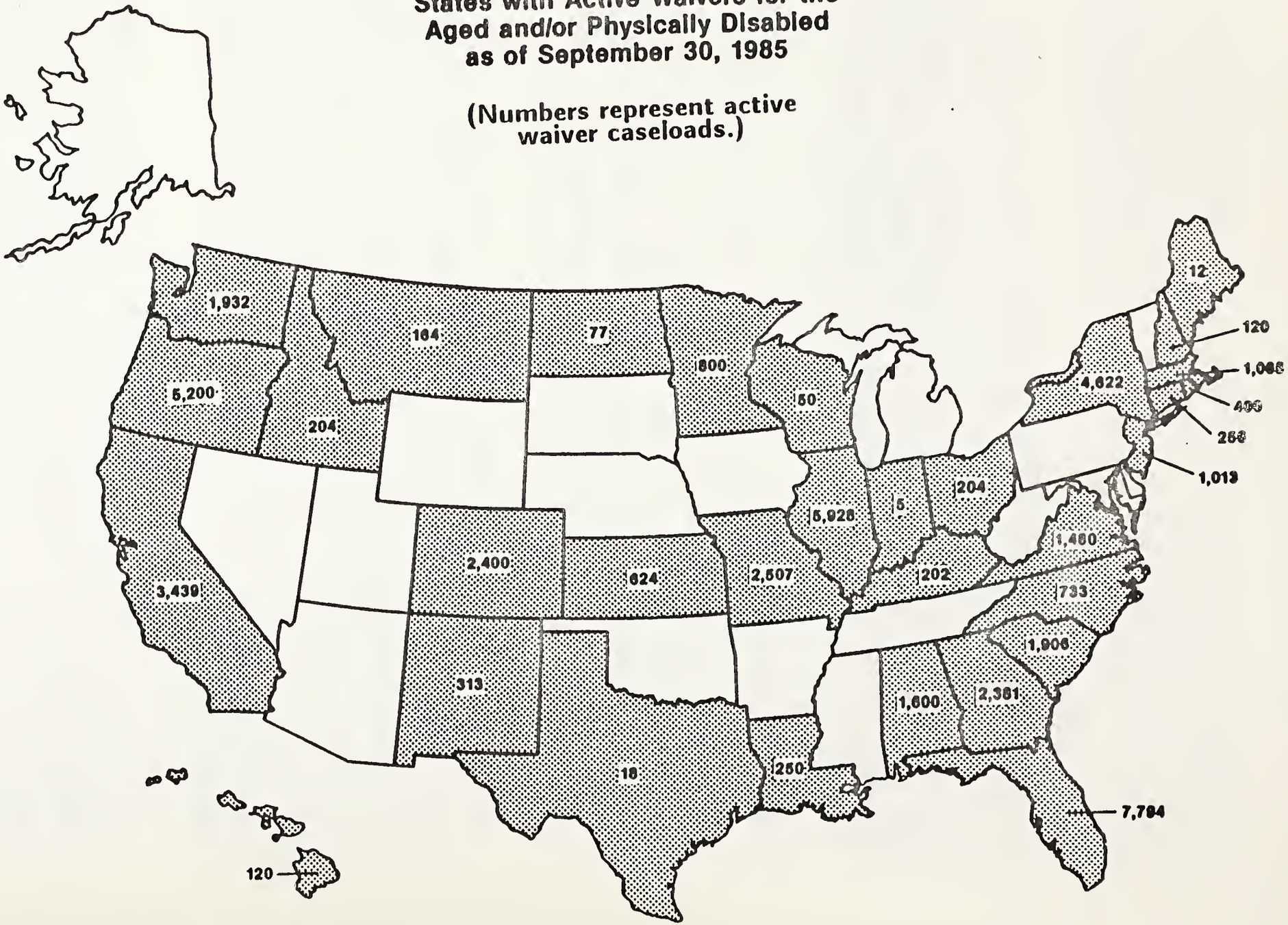
In Federal FY 1985 forty-two States were providing a broad array of health and social services under 75 distinct waiver programs. Of these, a total of 34 programs served the aged and/or physically disabled (A/D), 35 programs cared for the developmentally disabled and/or chronically mentally ill (DD/CMI), and six combined programs served both population groups (A/D-DD). As indicated in Exhibit 2-3, all programs taken together had a cumulative total enrollment of 124,260 persons from their implementation date through September 30, 1985. Nearly three times as many aged/physically disabled persons participated than clients with developmental disabilities/mental illness.

As evidenced in Exhibit 2-3, the size of current waiver programs varies widely among the States. As of September 30, 1985, States reported an active caseload of 47,819 aged/disabled waiver clients, 21,109 developmentally disabled clients and 1,109 persons with a diagnosis of chronic mental illness, for a total of 70,037. Waiver programs for the A/D comprise approximately two-thirds of the total caseload, while the DD/CMI programs account for about one-third. This ratio is not surprising

EXHIBIT 2-1

States with Active Waivers for the Aged and/or Physically Disabled as of September 30, 1985

(Numbers represent active waiver caseloads.)

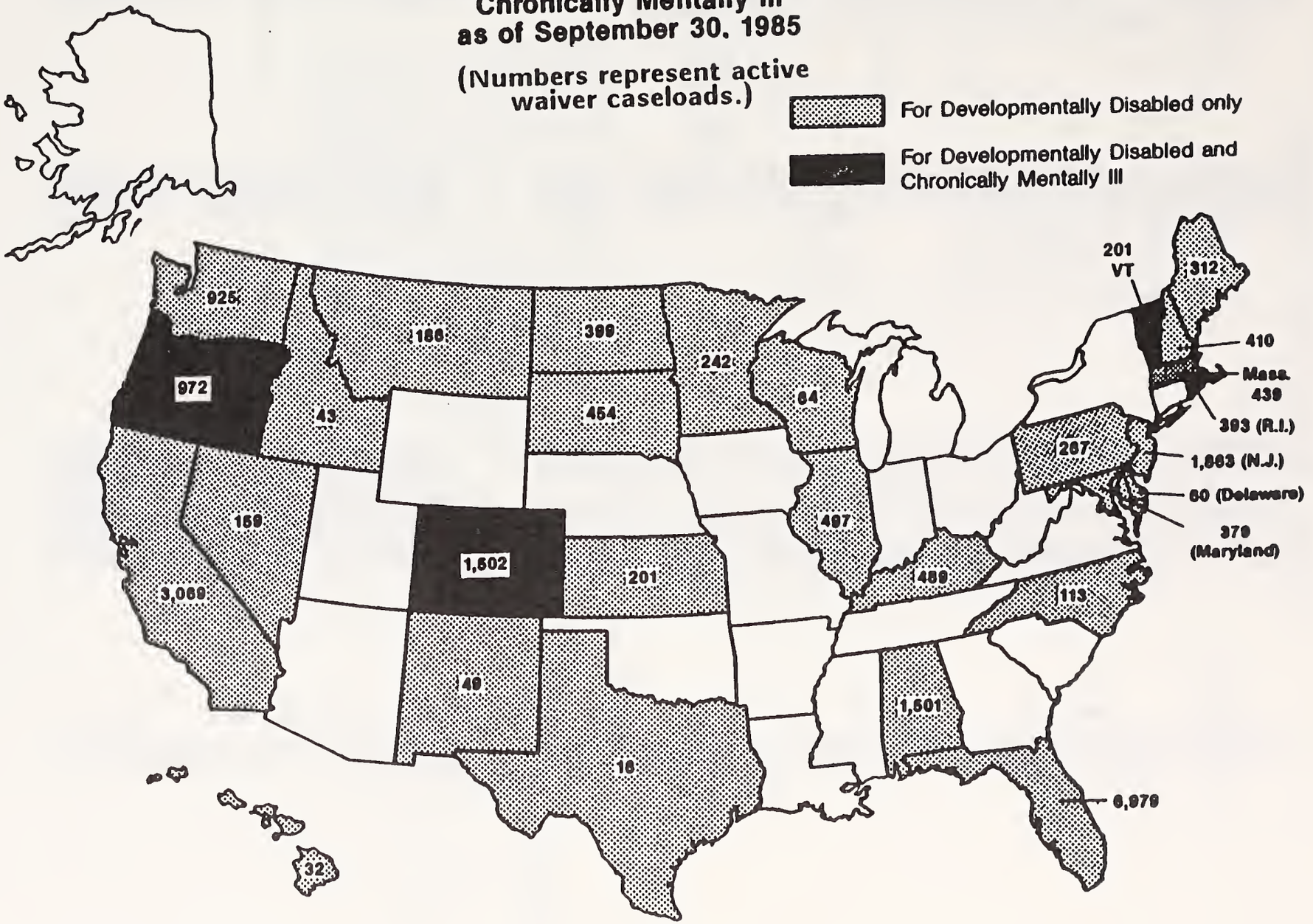


Source: La Jolla Waiver Survey (1985)

EXHIBIT 2-2

States with Active Waivers for the Developmentally Disabled and/or Chronically Mentally Ill as of September 30, 1985

(Numbers represent active waiver caseloads.)



Source: La Jolla Waiver Survey (1985)

AND ENROLLEES

A/D Waiver Programs	Effective Date	Total Enrollees Ever as of 9/30/85	Caseload on 9/30/85 a/
AL	10/01/84	1780	1600
CA	07/01/83	4800	3331
CA	07/01/83	161	108
CN	10/01/82	1060	256
CO	07/01/82	5500	2400
FL	04/01/82	25696	7507
FL	07/01/85	351	287
GA	10/01/81	5630	2381
HI	08/01/83	49	28
HI	08/15/83	161	92
IA b/c/	01/10/82	78	0
ID d/	01/01/84	217	204
IL	07/01/83	11925 e/	5928
IN	09/01/84	6	5
KS d/	03/22/82	1372	624
KY	07/01/83	389	202
LA	01/07/85	450	250
MA	07/01/83	83	65
MA	01/01/83	1231	1000
ME	05/01/85	24	12
MN	07/23/82	1900	800
MO	01/01/84	26	17
MO	04/22/82	4335	2490
MT d/	07/01/83	242	164
NC	07/01/82	1044	733
ND	10/01/83	180	77
NH	07/01/84	167	120
NJ	10/01/83	1666	1013
NM	07/01/83	509	313
NY	01/01/83	4734 f/	4622
OH	07/01/84	350	204
OR g/	12/23/81	5304	5200
RI	01/01/82	850	400
SC	10/01/84	3500	1906
TX	01/01/83	43	18
UT b/c/	10/20/82	8	0
VA	06/18/82	1165	1480
WA	01/01/83	4596	1932
WI	01/01/85	50	50
WV b/d/	07/01/82	297	0
D/D Waiver Programs			
AL	10/01/82	1850	1501
CA	07/01/82	3812	3069
CO	10/01/82	1379	1169
DE	07/01/83	72	60
FL	04/01/82	8263	6979
HI	07/01/83	33	32
ID d/	01/01/84	45	43
IL	12/01/83	542	497
KS d/	03/22/82	442	201
KY	04/01/83	568	489
LA b/	04/01/82	3250	0
MA	01/01/84	563	439
MD	02/13/84	418	379
ME	07/01/83	312	312
MN	07/01/84	246	242
MT d/	12/01/81	190	186
NC	07/01/83	129	113
ND	04/01/83	495	399
NH	09/01/83	425	410
NJ	10/01/82	2105	1863
NM	07/01/83	55	49

EXHIBIT 2-3 (cont.)

NUMBER AND TYPE OF WAIVER PROGRAMS
AND ENROLLEES

D/D Waiver Programs	Effective Date	Total Enrollees Ever as of 9/30/85	Caseload on 9/30/85 a/
NV	07/01/82	556	159
OK	01/01/85	0	0
OR f/	12/23/81	1886	400
PA	07/01/83	157	157
PA	07/01/83	112	110
RI	07/01/83	286	238
SD	06/01/82	712	454
TX	09/01/85	18	18
VT	04/01/82	234	152
WA	12/01/83	1038	925
WI	10/06/83	66	64
WV b/d/	07/01/82	50	0
CMI Waiver Programs			
CO	10/01/82	362	333
OR b/	12/23/81	875	572
RI	07/01/83	185	155
VT	04/01/82	600	49
Totals:		124260	70037
Sub-total A/D:		91929	47819
Sub-total DD:		30309	21109
Sub-total CMI:		2022	1109

a/ For several States the date for which caseload has been reported is slightly different.
b/ Program has been terminated.
c/ These States' programs are reported as A/D programs. Although they are combined programs, State was not able to segregate data.
d/ Enrollees in these States were reported separately although the programs are combined programs.
e/ This figure represents total unduplicated recipients in Year 2 of Illinois' waiver, not enrollees.
f/ This figure represents total unduplicated recipients in Year 3 of New York's waiver, not enrollees. Sum is inflated because it contains waiver service recipients plus State plan service recipients.
g/ This figure represents total unduplicated recipients in Year 4 of Oregon's waiver, not enrollees.
h/ This figure represents total unduplicated recipients in Year 2 of Oregon's waiver, not enrollees.

Source: La Jolla Waiver Survey (1985)

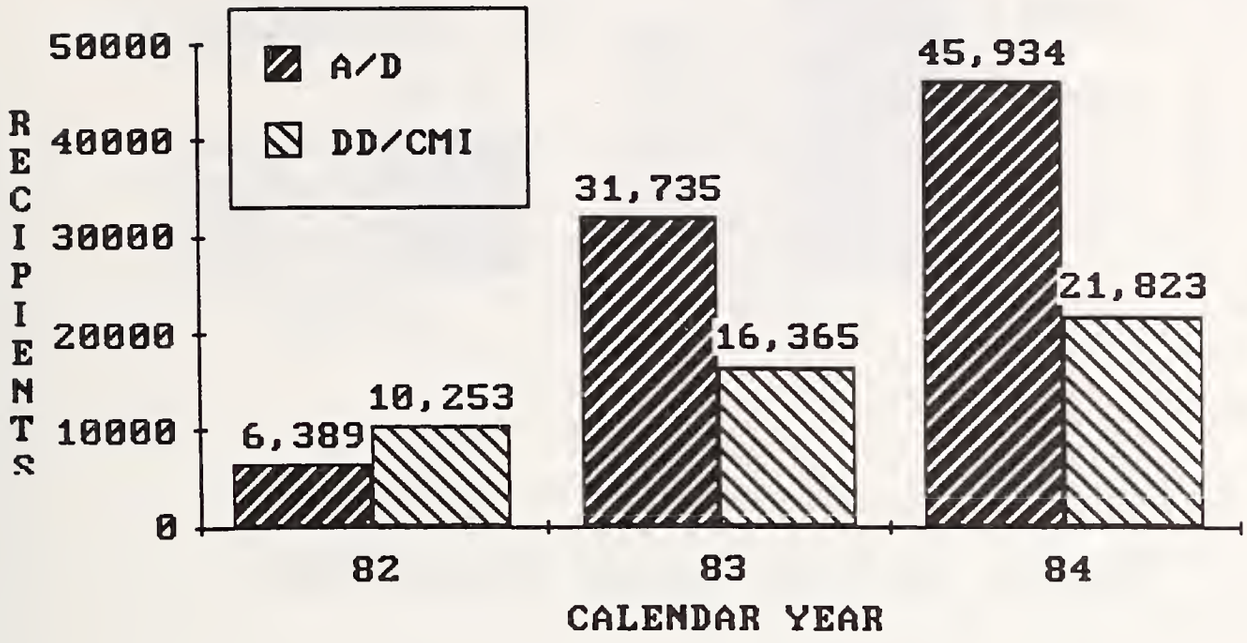
given the relative representation of the elderly in the population at large. Florida and Illinois have the largest A/D programs, and Florida and California have the largest waivers serving the DD/CMI groups. Five States (California, Florida, Illinois, New York and Oregon) represent 56 percent of the total A/D caseload; while the five largest DD/CMI programs (Alabama, California, Colorado, Florida and New Jersey) account for 66 percent. The average size of a waiver serving the aged/disabled was 1,195, compared to 542 for the developmentally disabled/mentally ill.

The growth of the Medicaid 2176 waiver programs since 1981 has been marked. The annual recipient count has climbed steadily from 1982 through 1984 for both the A/D and DD/CMI population groups (see Exhibit 2-4). A/D recipients of waiver services have increased from 6,389 to 45,934, a rise of approximately sevenfold. During the same period, DD/CMI recipients have doubled from 10,253 to 21,823.

An interesting finding regarding turnover in the enrollee population is presented in Exhibit 2-5. It is clear that aged and/or physically disabled persons are more likely to leave waiver programs either in response to changed needs or due to death, than are their counterparts in the DD/CMI waivers. The considerably lower turnover rate of developmentally disabled clients has important implications over the long term. Because the DD/CMI sub-group is truly a long-term waiver population, it will become increasingly harder for States to find slots for new entrants.

Generally speaking, waiver program penetration rates (defined as the ratio of waiver recipients to nursing home residents plus waiver recipients), are not very high at present, indicating that waiver programs would have considerable room to expand. DD waiver program penetration rates varied dramatically from 2.7 percent in Wisconsin to 68.4 percent in Florida, with an overall penetration rate nationwide of 23.0 percent. The level of program penetration in DD waivers is substantially higher than rates in A/D waivers, which range from less than 1.0 percent to 15.5 percent, with an overall rate of only 3.0 percent. (The discussion of penetration rates is continued in Chapters Three and Four.)

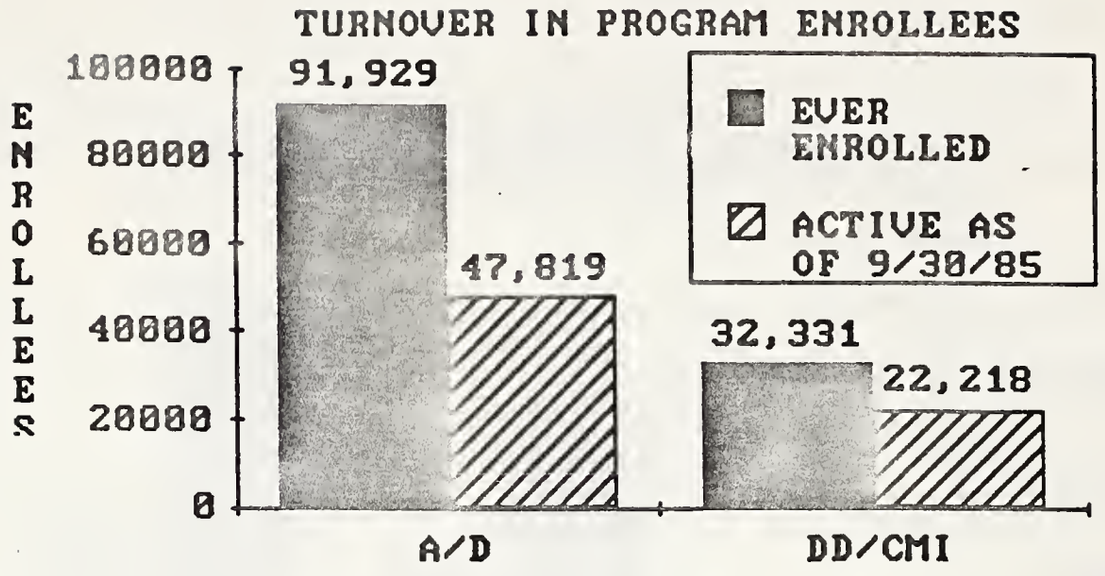
EXHIBIT 2-4
GROWTH IN WAIVER PROGRAMS[a/]
Number of Undup. Recipients by Year



a/ Recipient counts for each calendar year are based on waiver implementation dates (i.e., the number of recipients in a state with a waiver implementation date of March 1983 are counted in calendar year '83).

Source: La Jolla Waiver Survey (1985)

EXHIBIT 2-5



Source: La Jolla Waiver Survey(1985)

WAIVER SERVICES

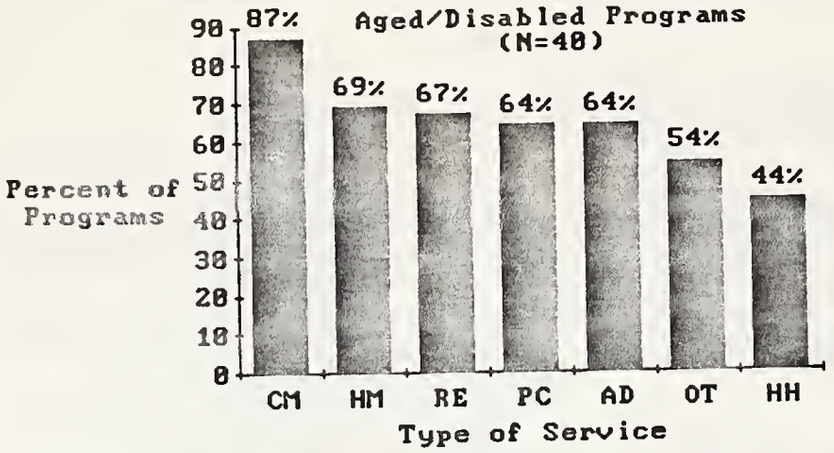
The Section 2176 legislation allows States considerable flexibility to decide what services to offer and how to define those services. The survey asked States to indicate which services were approved by HCFA under their individual waivers during Federal FY 1985. The results are reported in Exhibit 2-6.

Significant differences appear between A/D and DD/CMI waivers concerning the relative importance of specific home and community-based services. In structuring their A/D waiver programs, States have generally decided on the following ranking of service priority: (1)Case Management, approved in 87 percent of the programs; (2)Personal Care, Homemaker, Respite and Adult Day Health Care, approved in 60-70 percent of the programs; and (3) all other services, which are available in fewer than half of the waivers. Turning to the DD/CMI waivers, a different picture of client need is presented. For this population, service priorities have been assigned as follows: (1)Habilitation, approved in 89 percent of the programs; (2) Case Management and Residential Services, available in 84 percent of the programs; and (3) all other services, which are available in 60 percent or less of waiver programs. (However, as will be explored in the following chapters, the extent to which a waiver service is "approved", differs from the degree to which it is actually provided and reimbursed for.)

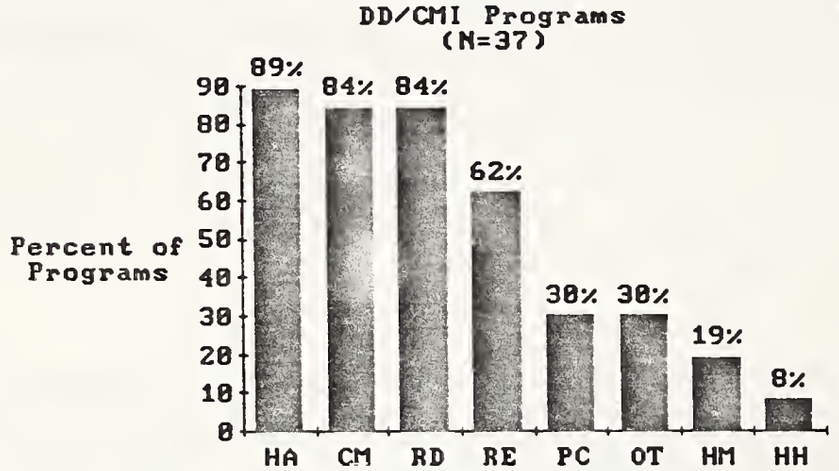
A brief word on service definition is in order. "Case management" comprises a number of client screening, assessment and quality assurance activities and will be examined further in subsequent chapters. Generally speaking, "Case Management" can have either a broad definition and be reimbursed as a distinct waiver service; or a more narrow definition, and be included as a State administrative cost within the Medicaid program. "Personal Care" and "Homemaker" services are similar in nature and include cleaning, bathing, grooming and feeding. The key difference between the two lies in the person rendering the care; "Homemaker" services tend to be provided by different personnel who, as the survey reveals, are higher paid. "Respite" care is provided literally to relieve the family and/or friends of waiver clients from their caregiving duties, and is usually offered for a period of hours or single days. "Adult Day Health" care denotes a variety of health and social services that are provided in a non-residential group setting. "Habilitation" is a generic

EXHIBIT E-3

APPROVED WAIVER SERVICES BY POPULATION GROUP



Key:
CM = Case Management
HM = Homemaker
RE = Respite
PC = Personal Care
AD = Adult Day Health
OT = Other Services, including:
Habilitation, Medical Supplies, Skilled Nursing, Therapies, Meals, and Transportation.
HH = Home Health Aide



Key:
HA = Habilitation
CM = Case Management
RD = Residential Services
RE = Respite
PC = Personal Care
OT = Other Services, including:
Medical Supplies, Skilled Nursing, Therapies, and Transportation.
HM = Homemaker
HH = Home Health Aide

Source: La Jolla Waiver Survey (1985)

term for a broad array of developmental training services tailored to the needs and disabilities of individuals so that they may function with greater independence. The specific types of training conducted under the rubric of "habilitation services" are related to the level and types of client deficiencies, and to their established goals and objectives.

WAIVER EXPENDITURES

Spending on waiver services has increased rapidly since the passage of Section 2176 legislation in 1981 as States have applied for and implemented numerous waiver programs. According to payment data compiled by HCFA Form 64, total Federal and State expenditures for all A/D and DD/CMI programs combined have grown as follows:

FY 1982 -- $ 3,651,903
FY 1983 -- $ 80,156,947
FY 1984 -- $181,091,369
FY 1985 -- $266,110,893

The La Jolla Waiver Survey asked States to report total expenditures for all waiver services delivered during Federal FY 1985, from October 1, 1984 to September 30, 1985. By requesting expenditure data according to date of service rather than payment, the survey provides a more realistic picture of costs for waiver services during a specific timeframe than does Form 64, which reports information by date of payment and, thus, may lump together expenditures from different years. States reported on the survey that a total of $96,015,448 was spent by all A/D waiver programs combined in FY 1985. Turning to the DD/CMI waiver programs, a total of $161,273,676 was spent for services delivered in FY 1985. This amounts to aggregate spending for waiver services of $257,289,124. (A more detailed discussion of waiver expenditures is presented in Chapters Three and Four.)

WAIVER ELIGIBILITY

Individuals who are entitled to medical assistance for skilled nursing or intermediate care facility services under a State's Medicaid plan are eligible to

receive services under the Section 2176 waiver provided they fall into one of the following three categories: (1) are aged and/or physically disabled, most often defined by the States as over 65 years of age; (2) are developmentally disabled or mentally retarded; or (3) are chronically mentally ill. In addition, States can choose to have broader eligibility rules for entry to the waiver based on several different eligibility options. There are five such major options as follows:

- A State can request the right to provide services of different type or intensity in different regions of the State,
- A State can elect to serve individuals qualifying as medically needy in addition to persons qualifying as categorically needy,
- A State can request the right to provide services to persons with an income of up to 300 percent of the Federal SSI payment standard,
- A State can request the right to exclude the income of parents for persons 18 years or younger or a spouse in determining eligibility, and
- A State can request the right to deny home and community-based services if these would be more costly than institutional services.

Exhibit 2-7 explains how States have chosen to exercise these five options. In more than half of all waiver programs, States have requested the right to provide different types of services in different regions of the State; to exclude the income of parents for persons 18 years or younger or a spouse in determining eligibility; and to deny waiver services if they would be more costly than institutional services. In 29 waiver programs, States have elected to serve individuals qualifying as medically needy in addition to those qualifying as categorically needy. In only a small minority of cases, have States incorporated the "300 percent" option in defining eligibility for the waiver.

WAIVER ADMINISTRATION

Finally, in the survey profile of Medicaid Section 2176 waiver programs, States were asked to define the locus of authority for administering each program (see Exhibit 2-8). While the lead responsibility is undertaken by a variety of public agencies, one pattern is clear: the entity most often cited as directing A/D programs is the State Medicaid agency, and the entity most often cited as being in

Exhibit 2-7

Coverage Options Exercised by States

	Major Options Exercised				
	Statewide[a]	Deeming[b]	Cost Cap[c]	Medically Needy[d]	300 Percent[e]
A/D Waiver Programs					
Alabama	No	No	Yes	n.a.	No
California	Yes	No	Yes	No	n.a.
California	No	No	Yes	Yes	n.a.
Colorado	No	No	Yes	n.a.	Yes
Connecticut	No	Yes	Yes	Yes	n.a.
Florida	No	No	No	n.a.	No
Florida	Yes	Yes	Yes	n.a.	Yes
Georgia	Yes	Yes	Yes	No	n.a.
Hawaii	Yes	No	No	Yes	n.a.
Hawaii	Yes	No	No	Yes	n.a.
Idaho[f]	No	Yes	Yes	n.a.	Yes
Illinois	No	No	Yes	Yes	n.a.
Indiana	Yes	No	Yes	n.a.	No
Iowa[f]	Yes	No	No	n.a.	Yes
Kansas[f]	No	Yes	Yes	Yes	n.a.
Kentucky	Yes	No	Yes	Yes	n.a.
Louisiana	Yes	No	No	No	n.a.
Maine	No	Yes	Yes	Yes	n.a.
Massachusetts	Yes	No	No	Yes	n.a.
Massachusetts	No	Yes	No	Yes	n.a.
Minnesota	No	Yes	n.a.	Yes	n.a.
Missouri	No	No	No	n.a.	No
Missouri	No	No	Yes	n.a.	No
Montana[f]	Yes	Yes	Yes	Yes	n.a.
New Hampshire	Yes	Yes	Yes	No	n.a.
New Jersey	Yes	Yes	Yes	n.a.	Yes
New Mexico	Yes	Yes	Yes	n.a.	Yes
New York	Yes	Yes	Yes	Yes	n.a.
North Carolina	Yes	Yes	Yes	Yes	n.a.
North Dakota	Yes	Yes	No	Yes	n.a.
Ohio	Yes	No	Yes	n.a.	No
Oregon	n.a.	n.a.	n.a.	n.a.	n.a.
Rhode Island	Yes	Yes	No	No	n.a.
South Carolina	No	Yes	Yes	No	n.a.
Texas	Yes	No	Yes	No	n.a.
Utah[f]	Yes	No	No	No	n.a.
Virginia	Yes	Yes	Yes	Yes	n.a.
Washington	Yes	Yes	Yes	No	n.a.
West Virginia	Yes	Yes	Yes	No	n.a.
Wisconsin	Yes	Yes	Yes	Yes	n.a.
DD Waiver Programs					
Alabama	No	No	No	n.a.	No
California	Yes	No	No	Yes	n.a.
Colorado	No	Yes	Yes	n.a.	Yes
Delaware	No	Yes	Yes	n.a.	Yes
Florida	No	No	No	n.a.	No
Hawaii	Yes	No	No	Yes	n.a.
Idaho[f]	No	Yes	Yes	n.a.	Yes
Illinois	No	No	Yes	Yes	n.a.
Iowa[f]	Yes	No	No	n.a.	Yes
Kansas[f]	n.a.	n.a.	n.a.	n.a.	n.a.
Kentucky	Yes	Yes	Yes	Yes	n.a.
Louisiana	No	No	Yes	No	n.a.

	Major Options Exercised				
	Statewide[a]	Deeming[b]	Cost Cap[c]	Medically Needy[d]	300 Percent[e]
DD Waiver Programs (continued)					
Maine	No	Yes	Yes	No	n.a.
Maryland	No	Yes	No	Yes	n.a.
Massachusetts	No	No	Yes	Yes	n.a.
Minnesota	Yes	Yes	No	Yes	n.a.
Montana[f]	Yes	Yes	No	Yes	n.a.
Nevada	No	No	No	n.a.	No
New Hampshire	Yes	Yes	No	No	n.a.
New Jersey	No	Yes	No	n.a.	Yes
New Mexico	Yes	Yes	Yes	n.a.	No
North Carolina	Yes	Yes	Yes	Yes	n.a.
North Dakota	Yes	Yes	No	Yes	n.a.
Oklahoma	No	Yes	Yes	Yes	n.a.
Oregon	n.a.	n.a.	n.a.	n.a.	n.a.
Pennsylvania	No	Yes	Yes	No	n.a.
Pennsylvania	Yes	Yes	Yes	No	n.a.
Pennsylvania	No	Yes	Yes	No	n.a.
Pennsylvania	Yes	Yes	Yes	No	n.a.
Rhode Island	No	Yes	Yes	No	n.a.
South Dakota	Yes	Yes	No	n.a.	Yes
Texas	Yes	No	Yes	No	n.a.
Vermont	Yes	Yes	No	No	n.a.
Washington	No	Yes	Yes	No	n.a.
West Virginia[f]	No	Yes	Yes	No	n.a.
Wisconsin	Yes	Yes	No	Yes	n.a.
CMI Waiver Programs					
Colorado	No	No	n.a.	n.a.	Yes
Oregon	n.a.	n.a.	n.a.	n.a.	n.a.
Rhode Island	Yes	Yes	No	No	n.a.
Vermont	Yes	Yes	No	Yes	n.a.
TOTALS[h]	43	47	46	30	13

SOURCE: La Jolla Waiver Survey (1985)

n.a. = Not Available

a/ "Yes" indicates that the State requests right to provide services of different type or intensity in different regions of the State.

b/ "Yes" indicates that the State requests right to exclude the income of parents for persons 18 years or younger or a spouse in determining eligibility for services.

c/ "Yes" indicates that the State requests right to deny home and community-based services if these would be more costly than institutional services.

d/ "Yes" indicates that the State plans to serve individuals qualifying as medically needy in addition to persons qualifying as categorically needy.

e/ "Yes" indicates that the State requests right to provide services to persons with an income of up to 300 percent of the Federal SSI payment standard.

f/ These are combined programs. [What is "combined"? A/D and DD or A/D and DD/CMI?]

g/ Although this is a combined program, respondent reported options only for the A/D portion.

h/ Totals for number of waiver programs do not match totals for columns answering "Yes" to coverage options because the 6 States with combined programs are counted twice in the program totals, but only once in the options columns.

EXHIBIT 2-8

STATE ADMINISTRATION OF WAIVER PROGRAMS
N = 75 PROGRAMS

A/D WAIVER PROGRAM	LEAD AGENCY	AGENCY REIMBURSED FOR ADMIN. SRVCS.[a/]	AGENCY EMPLOYING CASE MANAGERS
AL	M	A, HS	HS, LA
CA	A	H, HS, LA, P	H, HS, LA, P
CA	M	*	P
CN	A	*	H, HS, LA
CT	M	P	P
FL	A	A, LA	A, LA
FL	M	M, P	M, P
GA	A	*	*
HI	P	P	*
HI	M	M	M
IA [b/]	M	A, HS, OP	*
ID [b/]	M	*	*
IL	A	H, HS, OS, LA	H, HS, LA
IN	M	M	M
KS [b/]	OS	OS	OS
KY	M	H, P	H, P
LA	M	M	*
MA	A	LA	LA
MA	A	LA	LA
ME	A	LA	LA
MN	HS	H, HS, M, OP	H, HS, M, OP
MO	M	M	M
MO	M	A	A
MT [b/]	M	H, OP	H, OP
NC	M	H, HS, OP, LA	H, HS, OP, LA
ND	A	HS	HS
NH	M	*	HS, M
NJ	M	H, M, OS, LA	H, M, OS, LA
NM	HS	*	H, HS, OP
NY	M	H, OP, P	H, HS, M, OP, P
OH	M	HS, LA	H, HS
OR	HS	*	*
RI	M	M	M
SC	M	H, M	H, M
TX	M	OS	OS
UT [b/]	M	*	OP
VA	M	*	*
WA	OS	M, LA	M, LA
WI	M	HS	HS
WV [b/]	HS	M	M

D/D WAIVER PROGRAM			
AL	DD	NA	OP, P
CA	DD	NA	P
CO	DD	NA	P
DE	DD	NA	DD
FL	DD	NA	DD, P
HI	DD	NA	DD
IL	DD	NA	P
KY	M	NA	P
LA	DD	NA	*
MA	DD	NA	DD
MD	DD	NA	OP, P
ME	DD	NA	DD
MN	HS	NA	OP
NC	DD	NA	OP, P
ND	HS	NA	*
NH	DD	NA	P
NJ	DD	NA	P

EXHIBIT 2-8 (cont.)

STATE ADMINISTRATION OF WAIVER PROGRAMS

DD WAIVER PROGRAM	LEAD AGENCY	AGENCY REIMBURSED FOR ADMIN. SRVCS.[a/]	AGENCY EMPLOYING CASE MANAGERS
NM	DD	NA	DD
NV	HS	NA	DD
OK	DD	NA	DD
OR	DD	NA	*
PA	DD	NA	DD, OS
PA	DD	NA	OP
PA	DD	NA	OP
PA	DD	NA	*
RI	DD	NA	OS
SD	HS	NA	P
TX	DD	NA	*
VT	DD	NA	P
WA	DD	NA	*
WI	HS	NA	DD, OP, P
CMI WAIVER PROGRAM			
CO	OS	NA	P
OR	DD	NA	*
RI	OS	NA	DD
VT	OS	NA	P

* = Not Available.
NA= Question not asked of DD/CMI programs.

Key:
A = State Agency on Aging
HS = State or local Human Services Agency
M = State or local Medicaid Agency
OS = Other State Agency
OP = Other Public Agency
P = Private Agency
LA = Local Agency on Aging
H = State or local Health Department
DD = State DD/MR Agency

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a/ Services include a number of case management, assessment and quality assurance activities.
b/ These are combined programs.

Source: La Jolla Waiver Survey (1985)

charge of DD/CMI programs is the State Mental Retardation or Developmental Services agency. In addition, lead agency responsibility has almost always been placed in the hands of a single entity.

A different pattern emerges, however, if one examines which agency employs the waiver case managers, and which is reimbursed for these administrative services. In this instance, authority is much more diffuse, having been delegated by the lead agency to more than one agency in the majority of waiver programs. For example, Illinois operates one of the largest A/D waiver programs in the country, and reports that the following four public agencies are reimbursed under the waiver for the provision of such administrative services as case management, assessment and quality assurance activities: (1) the State or local health department; (2) the State or local human services agency; (3) the local agency on aging; and (4) another State agency. Similarly, no fewer than three of these entities are responsible for the hiring and supervision of case managers for waiver clients.

Also, one sees in Exhibit 2-8 that private and not public agencies are cited as being the provider of case management services in fully one-third of all programs. In California, Florida and New York, three of the largest A/D programs, private agencies are active in the waiver as employers of case managers.

Clearly, a great variety of State administrative practices have emerged in response to the Section 2176 waiver authority. The fact is that only one-third of the time is the lead agency also the agency reimbursed for administrative services and/or the agency employing case managers. Some States have reported that this organizational fragmentation increases the difficulty of managing waiver programs and hinders record keeping efforts.

CHAPTER THREE
WAIVERS SERVING AGED/PHYSICALLY DISABLED

This chapter presents an in-depth assessment of how the Medicaid 2176 waiver programs have functioned in each State, people served and dollars spent.

SCREENING AND ASSESSMENT ISSUES

A waiver program's potential cost-effectiveness rests upon its ability to accurately identify and treat persons who would otherwise use institutional long-term care services. There are a number of ways in which States can screen applicants to the waiver, and how individuals are selected could impact on overall cost-effectiveness. For instance, States could seek to admit aged or disabled persons directly from the community, or they could give priority to applicants entering from a hospital or nursing home. In addition, States have at their disposal a variety of screening mechanisms and selection criteria, some more stringent than others. The La Jolla Waiver Survey examined the screening methods used by States in considerable detail and formed the basis for observations concerning their appropriateness and efficacy.

Identifying the At-Risk Population

The enabling legislation specifies that the Section 2176 waiver program is to serve those who would be users of Medicaid-funded institutional care "but for" the provision of waiver services. The survey found that numerous formal criteria are employed by States in an effort to direct waiver services to just such a "but for" population. Examples of targeting criteria include: (1) enrollee points of entry; (2) Medicaid eligibility status; (3) the presence or absence of certain diagnostic/social situations; (4) the availability of informal supports; and (5) the relative cost of waiver treatment.

As evidenced in Exhibit 3-1, the survey found that the following four criteria were most often cited as State entry requirements either singly or in combination:

EXHIBIT 3-1

TARGETING CRITERIA FOR ADMISSION TO WAIVER PROGRAMS[a]

A/D WAIVER PROGRAM	MUST BE IN HOSPITAL	MUST BE IN SNF	MUST BE IN ICF	APPLYING FOR MEDICAID [b]	NEED BE CATEGORICALLY ELIGIBLE ONLY	AT RISK OF INST.	CERTAIN DIAGNOSTIC SITUATIONS [c]	CERTAIN SOCIAL SITUATIONS [d]	LACK OF INFORMAL SUPPORTS	CAN'T EXCEED COST CAP	PATIENT SAFETY
AL					X			X		X	
CA-A	X	X	X	X				X	X	X	
CA-A/D	X									X	
CN	X					X					
CO	X	X	X	X		X				X	X
FL-A/D					X						
FL-A				X						X	
GA	X	X	X	X			X				
HI-A				X				X			
HI-A/D					X						
IA										X	X
ID					X						
IL	X	X	X	X		X	X			X	
IN				X							
KS	X	X	X	X			X				
KY					X						
LA		X	X						X		
MA-A						X					
MA-A						X					
ME	X	X	X				X	X		X	X
MN	X	X	X	X						X	X
MO-D	X		X			X		X	X		
MO-A			X	X		X				X	X
MT				X		X		X			X
NC				X					X		
ND					X						
NH	X		X	X			X	X	X		
NJ				X						X	
NM					X						X
NY										X	
OH				X							
RI	X			X							
SC	X	X	X	X							
TX	X	X	X	X							
UT		X	X								
VA	X	X	X	X		X					
WA	X	X	X	X						X	X
WI					X					X	
WV				X			X	X	X		
TOTALS:	16	13	16	21	8	9	6	9	6	15	8

a/ Tables in Chapter 3 include all waiver programs which were in effect during this Survey's study year of 10/1/84 - 9/30/85.

b/ Persons who have applied for nursing home Medicaid coverage and/or nursing home placement.

c/ e.g., alcoholism, mental illness.

d/ e.g., lack of personal physician, housing inappropriate given mobility limitations.

Source: La Jolla Waiver Survey (1985)

the waiver applicant must be in a hospital; be in a skilled or intermediate care nursing facility; have applied for Medicaid nursing home coverage and/or placement; and/or be capable of receiving care within a specified cost ceiling. These criteria can be said to be fairly stringent; however, they were applied by only approximately half of the waiver programs.

Few A/D clients entered the waiver program from institutions. From Exhibit 3-2 it can be seen that only 14.4 percent of waiver participants came from hospitals or nursing homes. The great preponderance, some 83 percent, were living in a private residence when they entered a waiver. The waiver program cannot, thus, be seen as a mechanism for removing aged or disabled people from institutions. This would appear to make the task of substituting home and community care for nursing home care more difficult.

Twenty-five State waiver programs responded on the survey that a total of 36,878 applicants underwent waiver assessment from October 1, 1984 to September 30, 1985. There were a variety of reasons why persons were not admitted. Eight States reported that the highest percentage of clients were found ineligible because the applicant did not meet the level of care criteria. Seven States indicated that the highest percentage of clients were found ineligible because the applicant choose institutional care instead of home or community services. Other reasons given for non-admission were not as prevalent as the preceding two.

Link Between Nursing Home Screening and Waivers

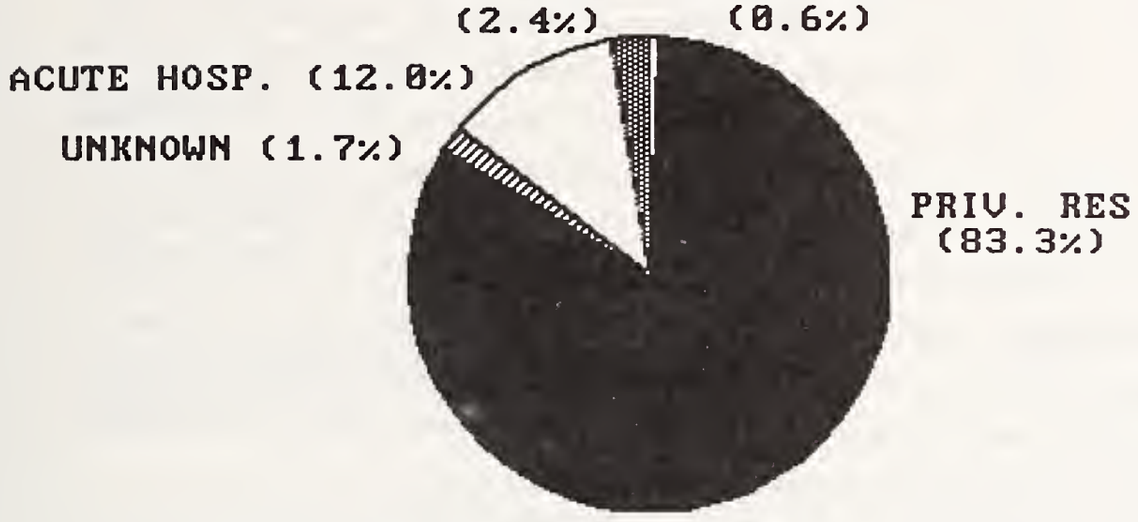
"Pre-Admission Screening" (PAS) as defined in the survey is the mandatory assessment of nursing home applicants who are Medicaid eligible or would become eligible within one month of the assessment. The survey sought to uncover the degree to which PAS systems are in operation, and whether States have linked PAS to the waiver assessment process in any systematic way.

It should be kept in mind that there is no single, uniform PAS model which States follow. Rather, the PAS concept is defined by the following core characteristics: (1) It is an assessment used to determine the need and appropriateness of nursing home placement that goes beyond financial eligibility

EXHIBIT 3-2

A/D ENROLLEE POINTS OF ENTRY

N = 14,192 CLIENTS



Source: La Jolla Waiver Survey (1985)

criteria and a physician's review to include assessment of a client's need by a disinterested third party; (2) The assessment must be on-site, i.e. a record review of client information is not considered PAS; and (3) The assessment has to be completed before admission. Beyond these central components, PAS programs can and do vary among the States. For example, PAS programs may or may not include case management, and PAS programs may or may not cover potential "spend-downs".

Our research hypothesis was that States which integrate PAS with waiver screening would probably be better able to identify and admit to the waiver only those individuals bound for nursing homes. There is preliminary evidence in support of this hypothesis: (1) PAS identifies the long-term care client closest to the point of nursing home entry. A national evaluation of community care demonstrations found that "Individuals identified as potential community care users through nursing home applications appear to have much greater likelihood of using nursing homes than similarly disabled individuals in the community who are not seeking institutional care." (Capitman, J. "Community-Based Long-Term Care Models, Target Groups, and Impacts on Service Use," The Gerontologist, August 1986, p.395.); and (2) The experience of the Colorado Foundation for Medical Care indicates that the number of nursing home placements significantly decreases if there is a PAS system in effect. The apparent reason for the success of well-designed PAS programs is that they take into account not only an applicant's health and functional status, but also the availability and strength of informal support, client lifestyle preferences, and fully explore alternatives to nursing home residency.

Only half of the A/D programs surveyed reported having mandatory PAS and directly linking it to the waiver assessment process (see Exhibit 3-3). In approximately one-third of these programs, it is still possible for some individuals to be admitted to a waiver program without ever going through PAS.

Exhibit 3-4 next addresses two important questions: "Do waiver programs have high or low acceptance rates?"; and "Does linkage with PAS appear to materially affect waiver admission rates?" In answer to the first research question, it can be seen that 10 out of 24 State respondents have experienced very high acceptance rates: two-thirds or more of all waiver applicants were accepted. It could be

EXHIBIT 3-3
FEATURES OF PRE-ADMISSION
SCREENING OF WAIVER APPLICANTS

SCREENING DEVICE	NUMBER OF PROGRAMS	AS PERCENT OF ALL A/D WAIVERS
Mandatory PAS a/	24	60%
PAS operational in all waiver counties	20	50%
PAS covers potential "spend-downs" b/	14	35%
Waiver assessment process is part of PAS	19	48%
No admission to waiver without going through PAS	13	33%
Contains all five of above screening devices	7	18%

a/ Pre-Admission Screening (PAS) is a comprehensive, mandatory assessment of nursing home applicants who are Medicaid eligible or would become eligible within one month of assessment.

b/ "Spend-downs" are defined as individuals who are not immediately eligible for Medicaid, but would deplete their own resources to become Medicaid eligible within a period of time after entering an institution.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-4

PERCENT OF A/D WAIVER APPLICANTS
ACCEPTED TO WAIVER PROGRAMS

N = 40 PROGRAMS

STATES WITH PAS PROGRAM a/	PERCENT ACCEPTED b/
CA-A/D	NA
CO	56%
FL-A/D	NA
FL-A	27%
GA	17%
IA	14%
IL	NA
IN	43%
KS	NA
MA-A	92%
MA-A	95%
ME	NA
MN	69%
MO-A	NA
MT	25%
NJ	93%
NY	NA
OH	27%
OR	NA
RI	NA
SC	18%
UT	NA
VA	34%
WA	NA
Average:	47%

STATES WITHOUT PAS PROGRAM	
AL	82%
CA-A	NA
CT	NA
HI-A	49%
HI-AD	31%
ID	NA
KY	89%
LA	88%
MO-D	81%
NC	NA
ND	NA
NH	91%
NM	48%
TX	5%
WI	67%
WV	20%
Average:	59%

NA = Not available.

a/ Pre-Admission Screening (PAS) is a comprehensive, mandatory assessment of nursing home applicants who are or would become Medicaid eligible within one month of assessment.

b/ Percentage of applicants assessed from 10/1/84 to 9/30/85 who were subsequently admitted to the waiver program during that period.

Source: La Jolla Waiver Survey (1985)

inferred that these screens were not highly selective. In four of these 10 programs PAS review was also required as part of the waiver screening process. Therefore, on the basis of this small sample it would be premature to conclude that the existence of PAS by itself deters inappropriate admissions to the waiver programs.

CLIENT CHARACTERISTICS

The survey examined the demographic and functional characteristics of waiver clients in considerable detail. Such factors as age, sex, marital status, and functional level have significance in the literature as predictors of nursing home utilization (Weissert, "Determinants of Institutionalization," 1982). Presumably, therefore, States will have done a better job of properly identifying waiver clients if client characteristics reveal a needy population at-risk of entering a nursing home.

Age and Marital Status

As highlighted in Exhibit 3-5, the A/D waiver programs were serving a predominantly elderly population as recently as September 30, 1985. Four-fifths of all waiver clients were 65 years of age or older, and one-fifth of clients were 85 or above. The A/D waiver population was also overwhelmingly female (75 percent).

Only 19 percent of aged/disabled waiver recipients were married and living with their spouses. The remainder were either divorced/widowed/separated (72 percent) or were never married (9. percent). The picture of A/D clients presented is primarily one of elderly women either living alone or without a spouse.

Health and Functional Status

The survey delved into the extent and nature of functional dependency among A/D clients. State respondents were asked to categorize waiver populations in the most severe dependency category which applies on a scale of four (see Exhibit 3-6). These four functional categories appear in a continuum and represent a compressed version of the well-known Activities of Daily Living (ADL) scale.

EXHIBIT 3-5

WAIVER PROGRAM CLIENTS BY
AGE, SEX, AND MARITAL STATUS a/

CATEGORY	CLIENT POPULATION (ENROLLEES)	POPULATION AS A PERCENT OF ALL A/D WAIVER CLIENTS b/c/
AGE: (N = 22)		
0 - 34	901	4%
35 - 64	3996	16%
65 - 74	6206	25%
75 - 84	8478	34%
85+	5432	22%
SEX: (N = 25)		
MALE	6419	25%
FEMALE	19056	75%
MARITAL STATUS: (N = 19)		
MARRIED	2731	19%
NEVER MARRIED	1285	9%
DIVORCED/WIDOWED/ SEPARATED	10433	72%

a/ Defined as all enrollees in the program on 9/30/85.

b/ Total may not equal 100 percent due to rounding.

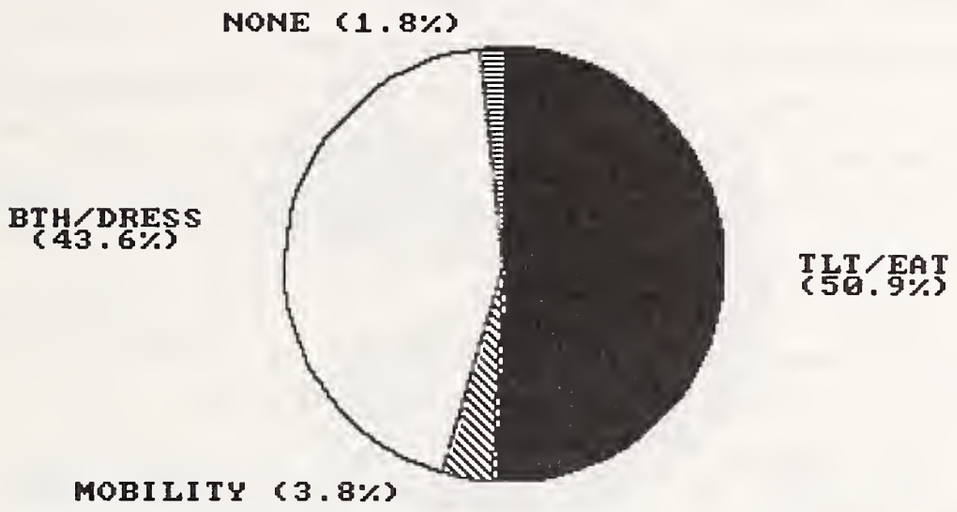
c/ This number represents the client population as a percent of those responding to this question.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-6

A/D CLIENTS BY ADL DEPENDENCY (PERCENT) a/

N = 10,358 CLIENTS



KEY: ADL LEVEL

TLT/EAT = Help needed in toileting and/or eating

BTH/DRESS = Help needed in bathing and/or dressing

MOBILITY = Help needed in mobility only

NONE = No help needed

a/ Defined as all new admissions in the program from 10/1/84 - 9/30/85.

Source: La Jolla Waiver Survey (1985)

The sample size was sufficiently large (one-half of all A/D waiver programs; actual data reported in 33 percent of programs responding, estimated data in 66 percent) to infer a functional profile of waiver clients. The findings reveal that A/D clients are characterized by a significant degree of impairment in their ability to carry out basic self-help activities. Specifically, 51 percent were placed in the most severe dependency level, requiring assistance in toileting and/or eating. Nearly as many, 44 percent, needed help in bathing and/or dressing, while 4 percent required help in mobility only. (It should be noted that the ADL scale is designed to be cumulative: the vast majority of persons placed in the two most severe categories probably also need assistance in mobility.) The States report that a mere two percent of A/D clients require no help at all in terms of ADLs.

Survey respondents were also asked to categorize enrollees in terms of their primary diagnosis. Half of all A/D waiver programs reported usable data, with data being actual in 33 percent of cases and estimated in the remaining 66 percent of cases. Of all enrollees for whom conditions were reported, the leading diagnosis was circulatory disorders, prevalent in 37 percent of client cases. Forty-four percent of the remaining clients were fairly evenly distributed among four diagnoses: nervous, respiratory and musculoskeletal disorders and cancer/genitourinary maladies, as catalogued in Exhibit 3-7. Only five percent of A/D waiver clients were reported to suffer from mental disorders.

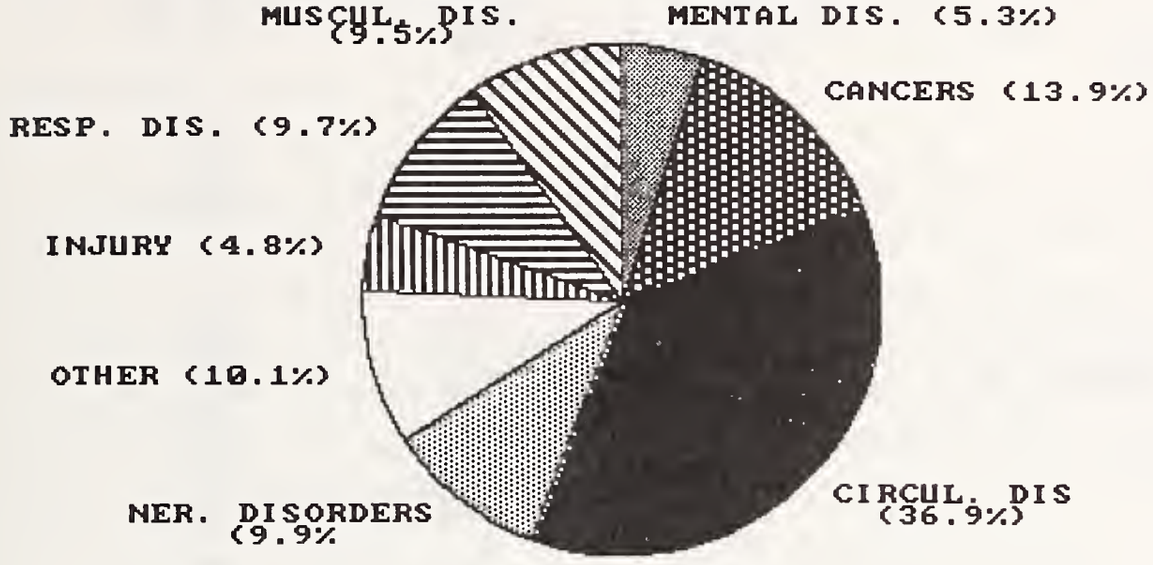
Waiver Clients, Nursing Home Residents and Impaired Elderly Living at Home

When the results of the survey are compared with equivalent socio-demographic and functional characteristics of the elderly in other settings, some interesting findings emerge. In general, it appears that waiver client characteristics are noticeably more like those of nursing home residents than they are like impaired elderly living in the community. Exhibit 3-8 compares characteristics of waiver clients from the La Jolla Survey with nursing home residents and impaired elderly living in the community. It can be seen that aged persons who are impaired yet continue to live at home comprise the youngest age group. Those over 85, the "oldest of the old," are most likely to reside in nursing homes; while the relative age of waiver clients lies between the two. In all three groups women outnumber men by significant margins. Not surprisingly, the elderly living at home are the

EXHIBIT 3-7

PERCENT OF A/D CLIENTS BY PRIMARY DIAGNOSIS [a]

N = 14,412 CLIENTS



[a] Defined as all new admissions in the program from 10/1/84 - 9/30/85

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-8

COMPARISON OF ELDERLY WAIVER CLIENTS,
NURSING HOME POPULATION, AND
IMPAIRED ELDERLY IN THE COMMUNITY

	WAIVER CLIENTS a/ (%)	SNF/ICF RESIDENTS (%)	ELDERLY AT HOME (%)
AGE			
UNDER 65	19%	13%	---
65-74	25%	16%	44%
75-84	34%	36%	38%
85+	22%	35%	18%
SEX			
MALE	25%	29%	36%
FEMALE	75%	71%	64%
MARITAL STATUS			
MARRIED	19%	12%	44%
NEVER MARRIED	9%	19%	56% b/
DIVORCED/WIDOWED	72%	69%	---
ADL			
NO HELP NEEDED	2%	10%	27%
MOBILITY ONLY	4%	2%	9%
BATH/DRESS	44%	27%	20%
TOILET/EAT	51%	62%	44%
DIAGNOSIS			
MENTAL	5%	20%	NA
CANCER/GENITOURINARY c/	14%	9%	NA
CIRCULATORY	37%	40%	NA
NERVOUS	10%	4%	NA
MUSCULOSKELETAL	9%	4%	NA
RESPIRATORY	10%	2%	NA
INJURY	5%	3%	NA
OTHER	10%	10%	NA
NO CONDITION	NA	7%	NA
INCONTINENT	45% d/	45%	NA
RECEIVE INFORMAL CARE	83% e/	NA	89%
LOW INCOME f/	100%	54%	18%

NA = Not Available.

a/ Includes all A/D waiver clients who were enrolled in the program on September 30, 1985.

b/ This figure includes both "NEVER MARRIED" and "DIVORCED/WIDOWED."

c/ Includes cancer, digestive, blood, metabolic and genitourinary disorders.

d/ This figure represents an unweighted average of States' reported percentages of waiver clients who suffer from bowel or bladder incontinence.

e/ This figure represents an unweighted average of States' reported percentages of waiver clients who prior to enrollment were receiving care from "informal sources only" and "both formal and informal sources."

f/ All waiver clients defined as "low-income" because of their Medicaid eligibility. Nursing home residents are termed "low-income" if their primary source of payment was Medicaid and/or other government assistance. Impaired elderly at home considered "low-income" if they qualify under Supplemental Security Income program.

Sources: La Jolla Waiver Survey (1985), National Nursing Home Survey (1977), National Long Term Care Survey (1982)

most likely to be still married, belonging to the category of aged which is proportionately the youngest.

The findings with regard to ranking of ADL level are somewhat unexpected. While one would expect the aged living in the community to be the least likely to require assistance, one may not expect to see five times as many nursing home residents as waiver recipients placed in the independent category. The same pattern is demonstrated at the higher range of dependency also. The elderly living at home consistently require less assistance, while the waiver population is more impaired in one respect (bathing/dressing) and less impaired in another (toileting/eating) as the nursing home population. Clearly, the waiver population is a needy one. However, ADL rating in and of itself does not appear to be an adequate predictor of institutionalization.

Turning next to a consideration of how the waiver and nursing home populations compare with respect to primary diagnosis, there appears to be a broad similarity between the two groups. The one distinguishing fact is that nursing home residents are more likely to suffer from mental disorders than are their counterparts in the waiver program. However, in general terms, it is not possible to tell waiver clients from nursing home residents solely on the basis of primary diagnosis or, for that matter, the prevalence of incontinence.

On the question of which sub-group of the elderly is most likely to enjoy the informal support of family and/or friends, there is no distinction. Both the elderly in the waiver program and their counterparts living at home are equally likely to receive informal care.

The last variable considered in Exhibit 3-8 deals with income. All waiver recipients are low income by virtue of their being Medicaid-eligible. Nursing home residents were termed to be low income if their primary source of payment was either Medicaid or some other form of government assistance or welfare. Impaired elderly living in the community were considered low income if they qualify under the Supplemental Security Income program; i.e., if they are dual eligibles. Given this scale, waiver recipients are the poorest sub-group, followed by nursing home residents, while the aged at home are the most financially well off.

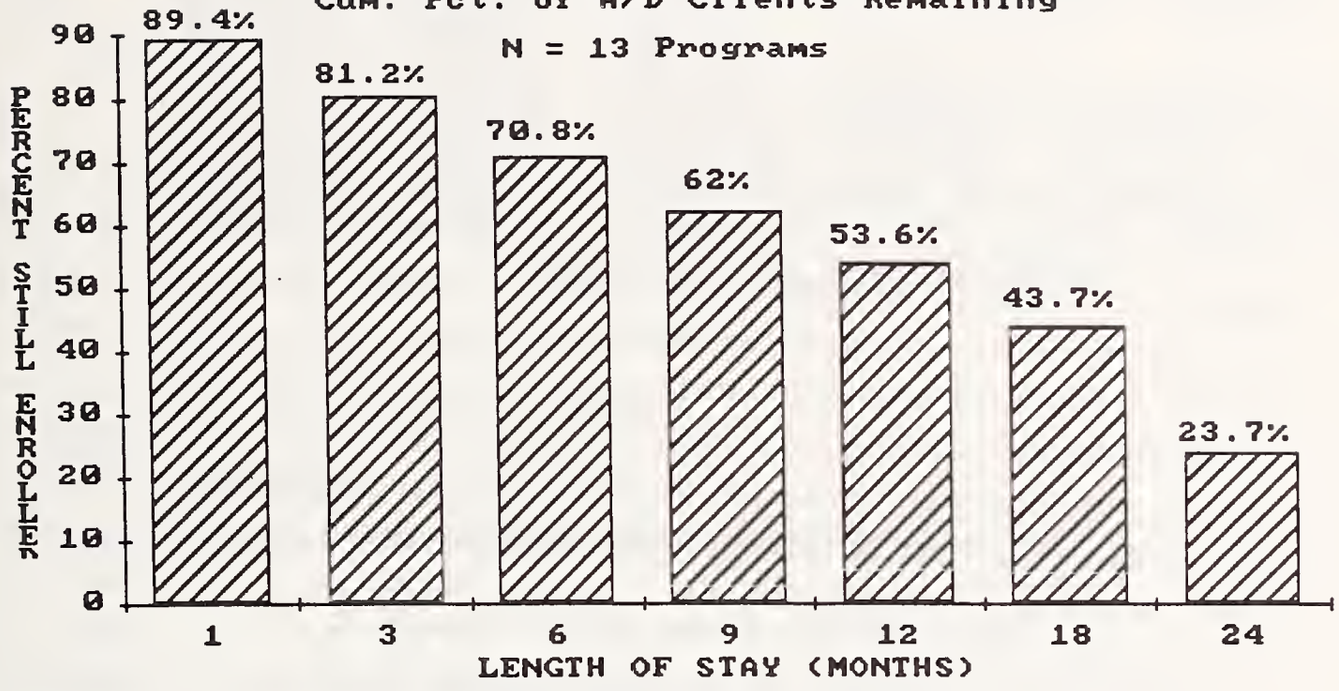
In conclusion, a close examination of Exhibit 3-8 demonstrates that waiver recipients are an elderly, frail group in need of assistance. At the present time, there appear to be no variables that distinguish between nursing home users and waiver clients. Except for the fact that they are less likely to suffer from mental disorders and more likely to live in poverty, waiver clients are largely indistinguishable from nursing home residents. This similarity between population groups represents both a potential opportunity and a problem to administrators of the waiver programs. On the one hand, accurate waiver client screening and identification could be promoted by the fact that the characteristics presented in Exhibit 3-8 overlap to the degree they do. However, the reverse may also be true: in the absence of distinguishing variables, how can one be certain which individuals are most at-risk of entering nursing homes and which would have remained in the community?

One way to remove some of the uncertainty in this area would be to know whether persons bound for nursing homes in the short term have informal care available to them to the same degree that waiver clients do. While no national data source exists to measure the presence or absence of informal care supports among nursing home residents, limited research in a handful of States indicates that individuals who were recommended to receive nursing home care were less likely to be receiving services provided by family members (Capitman et. al. "Study of the Public and Private Cost of Institutional and Community-Based Long-Term Care," Virginia Center on Aging, 1985; Wilke, D. "Comprehensive Adult Resources Evaluation System: Client Characteristics, Washington Department of Social and Health Services, 1984).

Length of Stay and Cause of Disenrollment

A "life-table" analysis of data reported in the survey, Exhibit 3-9, reveals that approximately one-fourth of A/D waiver clients participate in the program for six months or less. Another one-fourth will remain enrolled for between six and 18 months, with the rest staying active for longer periods. Generally, 2176 waivers have not been characterized by a very high rate of turnover. This is perhaps best revealed by comparing the length of stay experienced by nursing home patients.

EXHIBIT 3-9
LENGTH OF STAY DISTRIBUTION
Cum. Pct. of A/D Clients Remaining



Source: La Jolla Waiver Survey(1985)

Taken as a group, nearly two-thirds of nursing home patients will remain in a nursing facility for no more than six months; while, by the end of 18 months, some four-fifths will have been discharged (data based on National Nursing Home Survey, 1977).

The final exhibit in this section, Exhibit 3-10, deals with the circumstances under which A/D waiver participants leave the program. Based on our sample, the leading cause of disenrollment is not death as with the nursing home population, but entry into a nursing facility (38 percent). One-third of waiver recipients die while enrolled in the program. The remaining nearly one-third are disenrolled for a variety of reasons.

SERVICE UTILIZATION AND COST ISSUES

Expenditures by Type of Service

It is clear that the following three types of services are the backbone of the A/D waiver programs: (1) "Case Management", (2) "Personal Care" and (3) "Homemaker" services. As illustrated in Exhibit 3-11, these services were most often used by waiver clients during Federal FY 1985. Over one-half of A/D recipients received "Personal care" or "Homemaker" services. Only 26 percent of the A/D population in 1985 received "Case Management" as a formal waiver service. However, when States are considered which provide case management services to waiver clients funded out of Medicaid general administrative funds, the total rises to 54 percent of all A/D recipients.

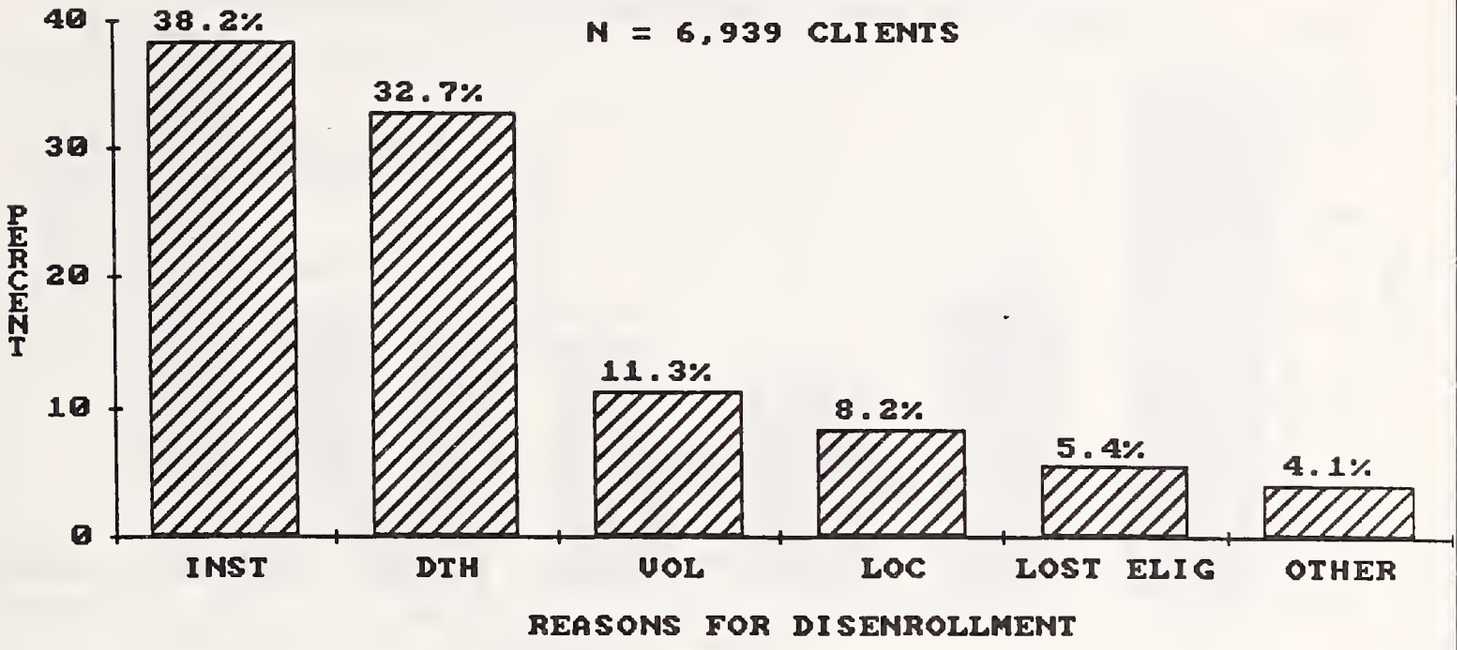
While States generally had the authority to deliver additional services (see Exhibit 2-6 in Chapter Two), the remaining categories of care were utilized much more sparingly. This appears to be in keeping with the care needs of waiver clients and the definition of services. For instance, "Respite Care" is intended to be provided on an intermittent basis only.

Turning to Exhibit 3-12, a total of $96,015,448 was spent by all A/D waiver programs combined in Federal FY 1985. The same three services which were most utilized also comprise the largest share of spending. "Personal Care" is responsible

EXHIBIT 3-10

A/D PROGRAM DISENROLLMENTS[a/]

N = 6,939 CLIENTS



KEY:

INST	= Institutionalized in Nursing Home.
DTH	= Death
VOL	= Client voluntarily disenrolled
LOC	= No longer met level of care criteria
LOST ELIG	= Lost Medicaid eligibility
OTHER	= Includes such developments as client moved out of service area; community care costs exceeded cost cap; and program lost track of client.

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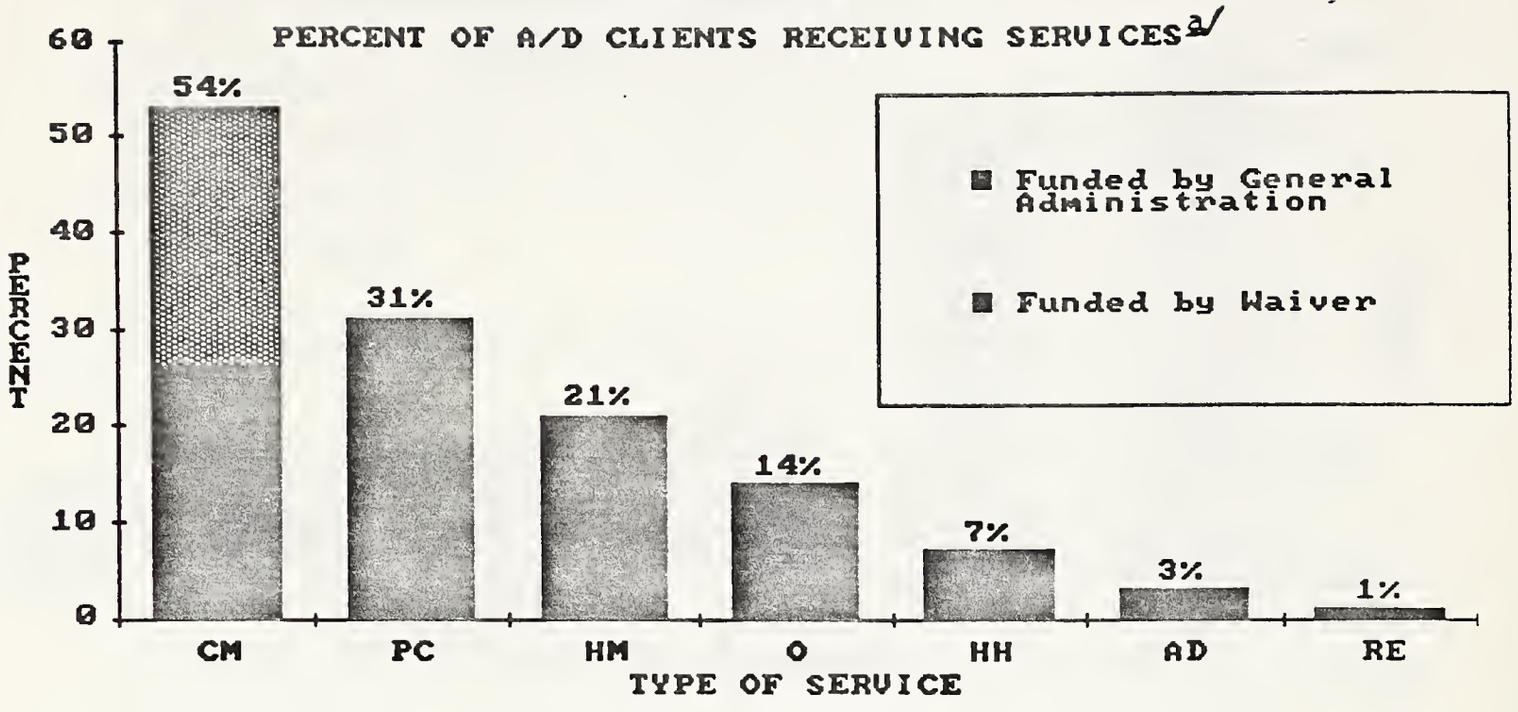
a/ Includes persons disenrolled between 10/1/84 and 9/30/85.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-11

PERCENT OF A/D CLIENTS RECEIVING SERVICES[a/]



KEY:

CM = Case Management
PC = Personal Care
HM = Homemaker
O = Other Services, including Skilled Nursing, Therapies, Medical Supplies, Transportation, Meals, etc.
HH = Home Health Aide
AD = Adult Day Health
RE = Respite

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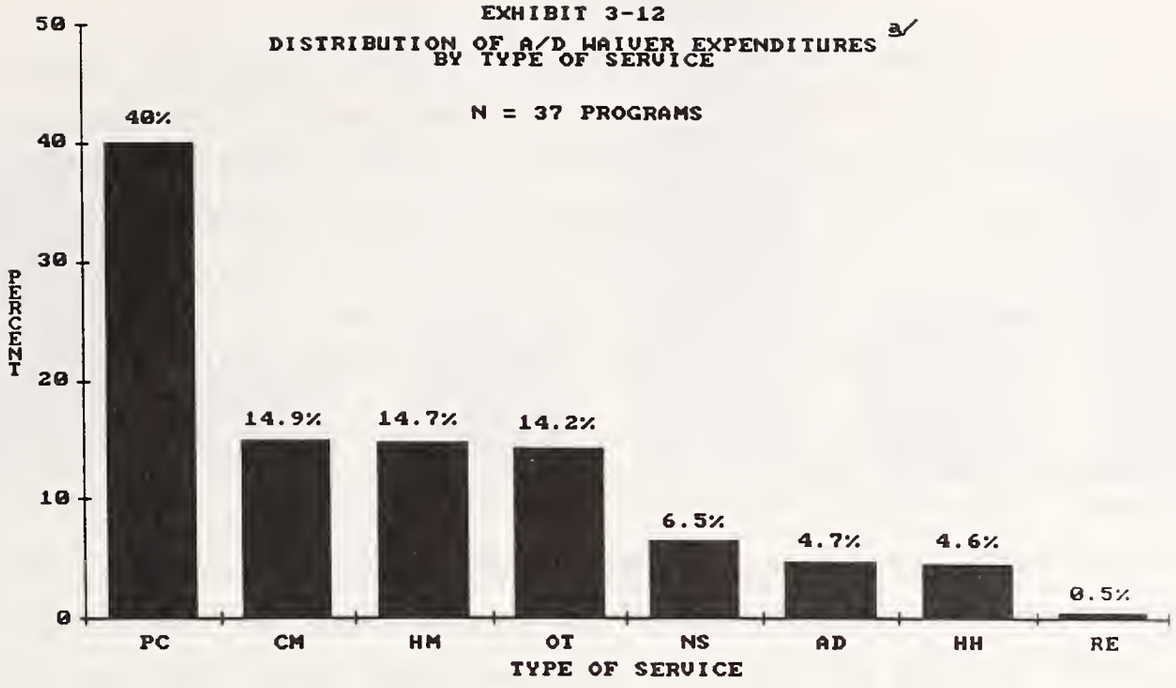
a/ Utilization data are for each waiver service delivered during the period 10/1/84 - 9/30/85. For several States the year reported is slightly different.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-12
DISTRIBUTION OF A/D WAIVER EXPENDITURES [a/]
BY TYPE OF SERVICE

N = 37 PROGRAMS



Total A/D 1985 Expenditures = $96,015,448

Personal Care	=	$38,412,541
Case Management	=	$14,264,464
Homemaker	=	$14.066,974
Other Services	=	$13,612,023
Not Specified	=	$ 6,234,773
Adult Day Health	=	$ 4,522,897
Home Health Aide	=	$ 4,447,403
Respite	=	$ 454,373

[a/] Expediture data are for each waiver service delivered during the period 10/1/84 - 9/30/85. For several States the timeframe reported is slightly different. In the case of Oregon, expenditures reported were for calendar year 1983. Massachusetts was unable to respond.

Source: La Jolla Waiver Survey (1985)

for 40.0 percent of the total or some $38,412,541 in FY 1985. In fact, when added to spending for "Homemaker" services (14.7 percent), (which in most State definitions overlaps with "Personal Care"), together they account for 55 percent of all A/D waiver expenditures.

Program spending for "Case Management" services is responsible for nearly 15 percent or some $14,264,464. It should be noted that this figure captures State spending where case management is defined as a distinct waiver service; it does not include instances where case management costs may be subsumed under general Medicaid administrative expenses. The multitude of services included under the "Other" category of care took 14.2 percent of the total, followed by "Adult Day Health" (4.7 percent), "Home Health Aide" (4.6 percent) and "Respite" (0.5 percent).

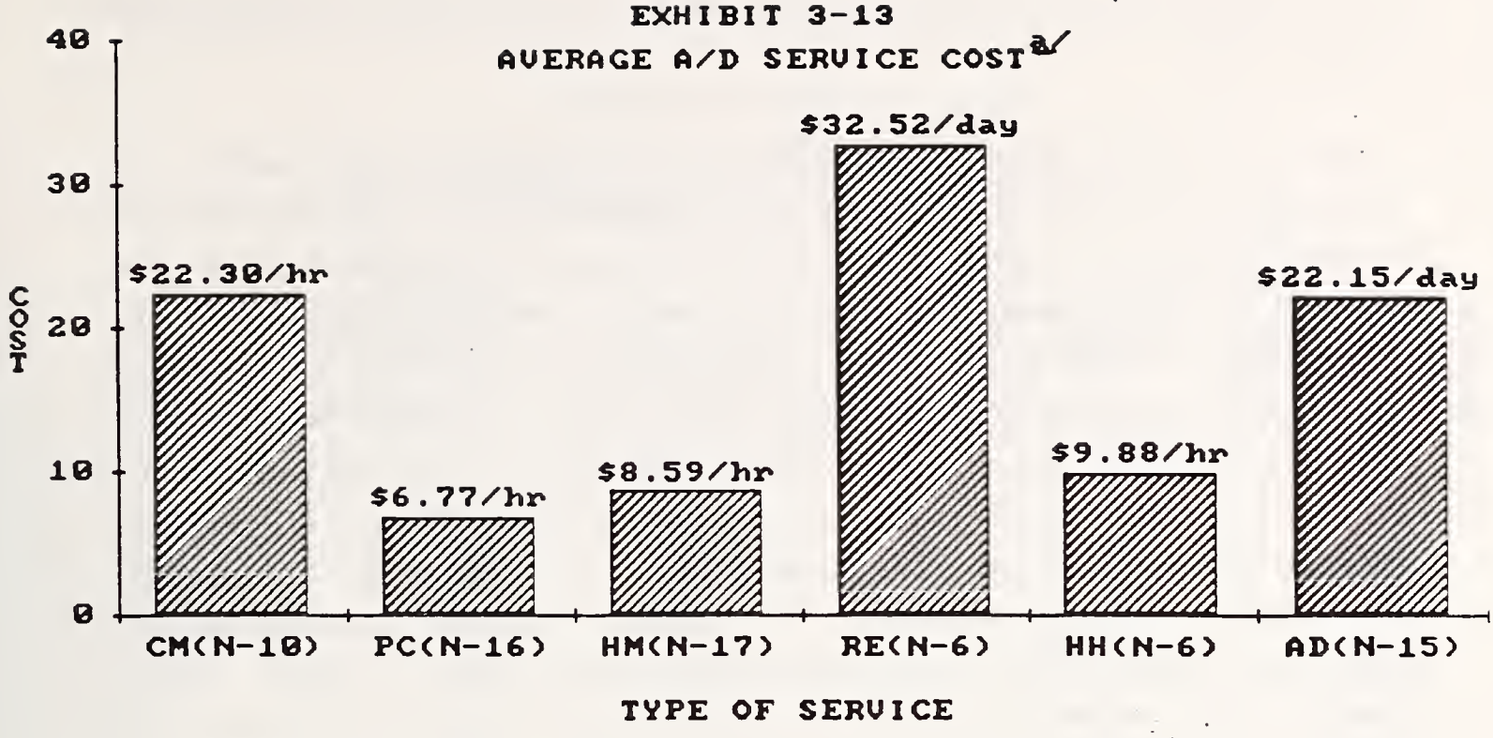
Unit Costs by Type of Service

This section places the discussion of overall waiver program spending in perspective by examining relative unit service costs among the States. The analysis of waiver spending will culminate in the succeeding section which explores total costs per waiver day of care, and compares it to per diem nursing home costs in the same State.

Exhibit 3-13 presents a comparison of the hourly and daily costs of selected waiver services as reported in the La Jolla Waiver Survey for FY 1985. "Case Management" costs tend to be expensive, averaging $22.30 per hour. While States most often reported paying for case management services on an hourly basis, other payment units were also employed such as per day, week or month and, in a few instances, on a per head or capitation basis. It is worth noting that the most widely utilized waiver service, "Personal Care", costs less per hour on average ($6.77) than similar services which also offer a combination of housekeeping and "hands on" care: "Homemaker" ($8.59) and "Home Health Aide" ($9.88). At least part of the reason for the cost differential here would appear to be the different levels of training which generally characterize the respective caregivers.

The average daily cost of "Adult Day Health" care and "Respite" care under the A/D waiver programs is not inexpensive: $22.15 and $32.52, respectively. However,

EXHIBIT 3-13
AVERAGE A/D SERVICE COST[a/]



KEY:

CM = Case Management
PC = Personal Care
HM = Homemaker
RE = Respite
HH = Home Health Aide
AD = Adult Day Health

---

a/ Data are for each waiver service delivered during the period 10/1/84 - 9/30/85. For several States the year reported is slightly different.

Source: La Jolla Waiver Survey (1985)

these two are the least frequently utilized among the major service categories (see Exhibit 3-11).

As set forth in Exhibit 3-14, actual "Case Management" costs reported vary widely, from a low of $7.00 an hour in West Virginia to a high of $43.84 an hour in Connecticut. In an effort to determine just what States are purchasing with their "Case Management" waiver dollars, one can compare the respective duties of the case managers in each of these States. As reported in the La Jolla Waiver Survey, the tasks performed by case managers in both States are essentially identical, and, therefore, do not appear to account for the significant cost differential. Neither can the difference be explained by reference to economies of scale, as the higher cost waiver, Connecticut, had an average monthly active caseload per case manager triple that of the lower cost waiver, West Virginia. One must look elsewhere for the exact reasons for the cost variance, e.g., training of case managers, waiver administrative structure, State standard of living, etc. What is important to understand in a policy context is that waiver programs with relatively high "Case Management" costs, both in terms of unit cost and relative to overall program expenditures, may find it more difficult to be cost-efficient and to achieve budget neutrality under Medicaid.

The cost of "Personal Care" services presented in Exhibit 3-14 also shows a considerable range among State programs, from a low of $3.85 an hour in Montana to a high of $14.84 in Kentucky. Once again, there is no obvious explanation for the considerable cost differential. State survey responses indicate that the definition of "Personal Care" services is even broader in the lower cost State, Montana, and that the waiver programs in both States served almost identical numbers of recipients over the same time period. Clearly, getting a handle on unit costs for the most popular waiver services should be an important factor in furthering the cost-efficiency of the Section 2176 program.

Comparative Costs of Waiver and Nursing Home Care

Exhibit 3-15 provides a revealing look at the relative cost of delivering waiver services under Section 2176. It indicates that based on the 16 A/D programs which reported adequate data, the average Medicaid cost of a waiver day of care in

Exhibit 3-14

COST PER RECIPIENT FOR CASE MANAGEMENT
AND PERSONAL CARE SERVICES

A/D WAIVER PROGRAM	CASE MGMT. COST/HOUR (N = 10 PROGRAMS)	CASE MGMT. AS A PERCENT OF TOTAL COST a/	PERSONAL CARE COST/HOUR (N = 16 PROGRAMS)	PERSONAL CARE AS A PERCENT OF TOTAL COST
AL	$12.00	8.4%	$6.00	0.2%
CO	$24.00	23.8%	$7.88	29.6%
CT	$43.84	35.6%	NA	NA
FL	NA	28.3%	$6.35	67.4%
GA	NA	NA	$13.14	38.5%
HI	NA	34.9%	$5.31	56.8%
ID	NA	NA	$5.00	100.0%
IL	NA	4.6%	$6.11	65.3%
KS	$7.84	14.1%	$3.67	67.8%
KY	$19.36	0.04%	$14.84	44.0%
ME	$26.04	10.5%	$5.76	26.0%
MN	$36.28	12.3%	$4.88	9.1%
MT	NA	28.6%	$3.85	46.5%
NC	$22.28	46.2%	$4.24	30.7%
NM	$24.35	11.8%	$6.82	87.1%
SC	NA	28.9%	$7.50	66.8%
VA	NA	NA	$7.00	100.0%
WV	$7.00	6.7%	NA	NA

NA = Not available.

a/ As a percent of the average annual total cost per waiver recipient for all services delivered during the period 10/1/84 - 9/30/85. For several States the timeframe is slightly different.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-15

COST OF WAIVER DAY VERSUS NURSING HOME DAY
N = 16

A/D WAIVER PROGRAM	WAIVER COST/DAY a/	NURSING COST/DAY b/	BREAK-EVEN RATIO c/
CO	$14.11	$29.41	48%
CT	$24.46	$49.96	49%
GA	$7.19	$22.68	32%
HI	$36.32	$77.28	47%
ID	$23.53	$55.09	43%
KY	$6.82	$39.52	17%
MN	$11.26	$40.28	28%
MO	$30.79	$33.85	91%
MT	$13.40	$32.85	41%
NH	$13.80	$56.12	25%
NJ	$17.45	$46.06	38%
NM	$17.34	$48.74	36%
OH	$17.09	$26.24	65%
SC	$5.15	$37.62	14%
TX	$5.18	$26.50	20%
VA	$16.59	$49.16	34%
AVERAGE:	$15.40	$40.12	38%

a/ As reported on the waiver survey for the time period of 10/1/84 - 9/30/85.
b/ Represents average of SNF and ICF expenditures by State during FY1985 as reported on the HCFA 2082 form.
c/ Derived by dividing "Waiver Cost per Day" by "Nursing Cost per Day."

Sources: La Jolla Waiver Survey (1985), HCFA 2082 Form for 1985.

Federal FY 1985 was $16.28. This compares to an average Medicaid cost of a nursing home day in the same States of $41.96.

Column one, "Waiver Cost/Day", was calculated by dividing total expenditures as reported on the survey by a waiver program during the period October 1, 1984 to September 30, 1985 by the total days of waivered coverage also reported for the same time interval. "Total days of waivered coverage" refers to the sum of enrollment days for all persons covered by the waiver. Two potential limitations to the data presented in column one should be kept in mind: (1) States may have inadvertently failed to report all expenditures; and (2) "Total days of waivered coverage" may overstate total days of waiver care because an individual could be eligible for waiver services while not necessarily require treatment on a given day.

Column two, "Nursing Cost/Day" was derived by first dividing total expenditures for SNF care during Federal FY 1985 by the total SNF days of care reported by States on HCFA Form 2082. The same procedure was repeated for ICF expenditures and days of care. The two products were then averaged to yield one combined cost of a nursing home day of care.

Column three, "Break-Even Ratio," was computed by dividing each waiver program's daily waiver cost by the corresponding State daily nursing home cost. The resultant ratio equals the percent of its waiver days of care that a State program needs to provide to persons who would have been admitted to nursing homes in order to be budget neutral. The potential "savings" of waiver over institutional care translates to an average break-even ratio of 39 percent.

This calculation is conservative in that it assumes that each nursing home day saved means that there was one institutional bed day left empty and unpaid for by Medicaid. However, in States where there is a nursing home waiting list, nursing home beds would not be left empty. And, if beds were to be filled by Medicaid recipients on the waiting list, Medicaid would not have avoided paying for institutional care, but, instead, end up paying for a nursing home bed in addition to waiver services. If this were the case, then the break-even ratios set forth in Exhibit 3-15 may actually need to be higher in order for a waiver program to be

cost-effective. On the other hand, it could represent a cost avoidance if the existence of the waiver results in fewer beds built in future years.

Missouri reports the highest break-even ratio of any State in one of its waiver programs. As described in Exhibit 3-15, it would need a targeting effectiveness rate of 91 percent to break-even. This particular waiver program is a relatively costly one as it is designed to serve only the physically disabled under 21, a group with comparatively high dependency and treatment needs. Of course, Missouri's break-even ratio must be regarded as a rough proxy because it is comparing the costs of caring for disabled waiver clients under 21 with the average nursing home costs of residents who are generally older than 21, and presumably less costly.

At the other end of the scale is South Carolina, with a break-even ratio of 14 percent and a reported waiver cost per day of only $5.15. However, in this instance the waiver is serving persons 18 years of age or older who are at a skilled or intermediate level of care, clearly a less dependent group. One other fact about South Carolina's program which may help explain its low overall waiver cost is that it reports providing relatively low cost case management services to all of its waiver recipients.

In conclusion, based on the results reported in Exhibit 3-15, State A/D waiver programs exhibit a wide variation in cost per waiver day. The average cost per day of waiver care ranged from $5.15 in South Carolina to $36.32 in Hawaii. The average daily cost of waiver care ranged from 14 percent of the average daily nursing home cost in South Carolina to 91 percent of nursing home costs in Missouri. While the States are not treating identical people in their waivers, the fact remains that some States have lower costs, and this is important because lower cost per waiver day implies that a lower targeting effectiveness rate will be needed to break-even. The lower this rate, the greater the likelihood that a particular waiver program will be budget neutral.

Paying Providers Under the Waiver

At the present time, the provision of alternative long-term care services under Section 2176 does not appear to have stimulated the development of alternative

provider reimbursement methods. For the most part, providers of waiver services are paid on a fee-for-service basis. "Fee-for-service" is defined as payment for each unit of service utilized. Fee-for-service rates may be set in advance, but payments are based on the actual amounts of services received. Three-fourths of the A/D waiver programs indicated that they rely on fee-for-service payment all or most of the time (see Exhibit 3-16).

Only nine waiver programs reported having non-traditional payment mechanisms as the dominant method. Of these, six employed a capitation system either for most waiver services or for case management only. "Capitation" is defined as payment rates set in advance for each client for a specific unit of time, e.g., per month. The same rate for a service applies to everyone approved to receive care, regardless of the volume of services they actually receive.

Four States (California, Iowa, New Mexico and Ohio) employed prospective reimbursement methods for all or most waiver services during FY 1985. "Prospective reimbursement" is defined as rates determined in advance, which are not subject to retroactive adjustment based on the actual amount of services rendered. These programs generally relied upon negotiated contracts between the State lead agency for the waiver and the relevant providers.

DELIVERY SYSTEM ISSUES

Waivers and the Nursing Home Delivery System

It is anticipated that A/D waiver programs will reduce the number of individuals who would otherwise be treated in nursing homes by offering appropriate alternative services in home and community settings. Accordingly, the survey examined whether the existence of Section 2176 waiver programs may have had the effect of reducing Medicaid nursing home bed occupancy rates, and thereby generating cost savings. Each State program was asked to indicate the total occupancy rate for Medicaid certified beds at the time of waiver approval, as well as the occupancy rate as of September 30, 1985. Most States were unable to answer the question. Of those who did, an equal number reported that occupancy rates had increased over the life of their waiver as had decreased or had remained unchanged (see

EXHIBIT 3-16

WAIVER SERVICE PAYMENT METHOD
N = 35 PROGRAMS

A/D WAIVER PROGRAM	FEE-FOR-SERVICE		CAPITATION		PROSPECTIVE	
	ALL SERVICES	MOST SERVICES	CM ONLY	MOST SERVICES	ALL SERVICES	MOST SERVICES
AL	X					
CA	X					
CA-D					X	
CO		X				
CT	X					
FL		X				
FL-A				X		
GA	X					
HI-A				X		
HI	X					
IA					X	
ID	X					
IL		X				
IN			X			
KS		X				
KY	X					
LA	X					
ME	X					
MN	X					
MO-D	X					
MO-R	X					
MT	X					
NC	X					
ND	X					
NH	X					
NJ	X					
NM					X	
NY		X				
OH			X			X
RI		X				
SC		X	X			
TX	X					
VA	X					
WA				X		
WV		X				
TOTALS a/	19	8	3	3	3	1

a/ Totals do not add to 35 because two States, Ohio and South Carolina, utilize a combination of provider payment methods.

Source: La Jolla Waiver Survey (1985)

Exhibit 3-17). At the present time, therefore, a lowering of nursing home occupancy rates seems unrelated to the implementation of a waiver program.

This result is not surprising given the fact that the total number of waiver recipients in a State is only a small fraction of the aged/disabled population as a whole. In empirical terms, the overall penetration rate of the 32 A/D waiver programs where the data was available was three percent in 1985. This figure was calculated by dividing the total caseload of these programs as of September 30, 1985 by the total nursing home recipients in the applicable States in Federal FY 1985 plus the waiver caseload. Nineteen of these waiver programs had penetration rates below three percent; ten experienced rates of between three and ten percent; and three had rates in excess of ten percent. This latter group is composed of Florida (15.5 percent), Connecticut (12.8 percent) and South Carolina (11.3 percent).

Another research issue which was addressed in the survey was whether or not waivers helped shorten the waiting period for Medicaid recipients seeking admission to nursing homes either from the community or from hospitals. While such an occurrence may not produce savings from nursing home days avoided in the short term, it may in the longer run by incrementally reducing the need for beds.

Roughly two-thirds of the waiver programs do not keep track of waiting periods or hospital back-ups. For those that did, no pattern emerges. Only two States--Minnesota and New Mexico -- reported a change in status as follows: waiting lists for nursing home entry had existed at the start of their waivers, but had disappeared by September 30, 1985; and, in one program, hospital back-ups in the waiver service area had been eliminated over the course of the waiver. Judging from the above, it cannot be observed whether the 2176 program has reduced the need for more nursing home beds.

In seeking to determine if waivers had any influence on the supply of Medicaid nursing home beds, the survey asked a series of questions as reported in Exhibit 3-18. Only seven A/D programs out of a universe of 40 were operating in States which had established a moratorium on the building of new nursing homes or the expansion of existing ones. Of these, Minnesota, New York and South Carolina

EXHIBIT 3-17

NURSING HOME OCCUPANCY AND WAITING PERIODS
OVER LIFE OF WAIVER

CATEGORY	NUMBER OF PROGRAMS	AS PERCENT OF ALL A/D WAIVERS
MEDICAID N.H. BED OCC. RATE a/		
-- INCREASED	5	13%
-- DECREASED	5	13%
-- UNCHANGED	6	15%
WAITING LIST IN COMMUNITY AT START OF WAIVER b/		
-- YES	14	35%
-- NO	14	35%
WAITING LIST IN COMMUNITY AS OF 9/30/85		
-- YES	12	30%
-- NO	12	30%
HOSPITAL BACK-UPS AT START OF WAIVER c/		
-- YES	11	28%
-- NO	12	30%
HOSPITAL BACK-UPS AS OF 9/30/85		
-- YES	11	28%
-- NO	13	33%

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a/ The total occupancy rate for Medicaid certified beds at waiver approval compared to the occupancy rate as of September 30, 1985.

b/ Defined as waiting list of Medicaid recipients in waiver service areas seeking institutional care. Excludes persons who are waiting for Medicaid eligibility determination.

c/ Defined as hospital back-ups in waiver service areas due to unavailability of nursing home beds for Medicaid patients.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 3-18

CHANGES IN STATE REGULATIONS
AFFECTING THE SUPPLY OF
MEDICAID NURSING HOME BEDS

CATEGORY	NUMBER OF STATES	NUMBER OF STATES INDICATING WAIVER WAS A FACTOR
MORATORIA ON N.H. BEDS:		
-- YES	7	3
-- NO	22	NA
CERTIFICATION STANDARDS:		
-- CHANGED TO INCREASE NUMBER OF BEDS	2	0
-- CHANGED TO DECREASE NUMBER OF BEDS	2	2
-- UNCHANGED	29	NA
LEVEL OF CARE CRITERIA		
-- MORE STRINGENT	3	3
-- LESS STRINGENT	0	0
-- UNCHANGED	29	NA

NA = Not Available

Source: La Jolla Waiver Survey (1985)

responded that the existence of the waiver program was a factor contributing to the decision. A fourth State, Washington, indicated that it made a downward adjustment on approved certificates of need due to the presence of the waiver program.

Very few States reported having changed their nursing home certification standards since implementation of the waiver. Of those that did, Florida and New York answered that they had been changed in such a way as to decrease the number of Medicaid nursing home beds, and that this change was caused in part by the existence of the waiver.

Finally, States have generally not altered their level of care criteria for nursing home admission since introduction of Section 2176. However, the three who did (Colorado, Georgia, and Missouri) made them more stringent, and attributed the decision, at least in part, to the existence of the waiver.

In summary, it appears that the 2176 waivers have had a limited impact on the larger long-term care delivery system. There are four possible ways to achieve cost savings by reforming the infrastructure: (1) Reduce the Medicaid nursing home occupancy rate; (2) Reduce hospital back-ups and waiting lists for Medicaid recipients to get into nursing homes; (3) Close beds and/or homes; and (4) Reduce the need for future beds. The survey reported no evidence that the 40 A/D programs have as yet played a role in any of the first three methods, but in nine cases State waiver officials have indicated that they have been a factor in reducing the need for more nursing home beds.

Waivers and Informal Care

The survey indicates that home and community-based services provided under Section 2176 waivers generally support and do not supplant informal sources of care. "Informal sources" are defined as care rendered by non-paid family members and/or friends.

In 23 out of 40 A/D programs, waiver services may not be provided to meet care needs of persons already being addressed by informal caregivers (see Exhibit 3-19).

EXHIBIT 3-19

EFFECT OF WAIVER PROGRAM ON INFORMAL CARE

INFORMAL CARE GUIDELINES	NUMBER OF PROGRAMS	AS PERCENT OF ALL A/D WAIVERS
1. Clients must have an informal caregiver to be admitted to waiver.	3	8%
2. Informal caregivers must contribute specified amount of time each week.	5	13%
3. Waiver services not provided to meet care needs already being met by informal caregivers.	23	58%
4. Waiver services provided to meet needs already being met ONLY IF informal care givers redirect their efforts.	6	15%

Source: LaJolla Waiver Survey (1985)

Several States require informal caregivers to contribute a specified amount of time each week, or to redirect their efforts as a condition of waiver eligibility. The crucial role of informal care in addition to waiver services is clearly illustrated by the fact that, on average, 83 percent of program clients admitted from a non-institutional setting were receiving long-term care services from informal sources before enrolling in the waiver.

OVERSIGHT AND QUALITY ASSURANCE

Role of Case Manager

Case managers are generally expected to play a key role under Section 2176, both in the screening of waiver applicants and in facilitating the use of services that will benefit recipients. Therefore, the survey questioned States on the design of their case management systems; it did not directly address the question of which case management systems are most effective.

State responses make possible for the first time a nationally-applicable description of actual case management responsibilities under the 2176 program. It can be seen from Exhibit 3-20 that these functions span a wide range of management, assessment and quality assurance activities. The great majority of A/D waiver programs stated that their case managers are involved in coordinating the delivery of waiver services, assisting waiver clients in obtaining non-waiver community services, and developing the initial care plan. In many cases only the case manager performs these duties, while in other instances he or she shares responsibility with another individual or individuals in the public or private sector.

Other major duties performed by case managers include assessing a client's progress and continued appropriateness in the waiver program; determining the cost of community care for waiver applicants; and monitoring the quality of care provided.

As examined earlier in this chapter, the costs of case management reported by the States vary widely. Also, only approximately one-half of A/D waiver recipients have a case manager to serve them in the complex role of both gatekeeper and

EXHIBIT 3-20

ROLE OF CASE MANAGER

CASE MANAGEMENT FUNCTIONS	NUMBER OF PROGRAMS	AS PERCENT OF ALL A/D WAIVERS
A. Comprehensive initial assessment/ screening of waiver program apps.	21	53%
B. Level of care determinations	10	25%
C. Determination of costs of community care for waiver applicants	26	65%
D. Final determinations of clients' acceptance into the waiver program	17	43%
E. Initial care plan development	29	73%
F. Assisting clients in obtaining non-Medicaid/non-waiver community based services, e.g., Meals-on-Wheels	30	75%
G. Coordination of delivery of waiver services	32	80%
H. Monitoring quality of care provided	24	60%
I. Review/approval of claims for waiver services (i.e., whether they correspond to services approved in care plan)	15	38%
J. Assessing client's progress and continued appropriateness in the waiver program	27	68%
K. Periodic level of care redetermination	12	30%
L. Determination of client cost-sharing liability and/or maintenance of client cost-share contribution records	10	25%

Source: La Jolla Waiver Survey (1985)

client advocate. While the data obtained from the survey do not allow any conclusions to be drawn regarding the success or failure of State case management systems under Section 2176, the following observation can be offered. Of the waiver programs which reported linking their waiver assessment process to PAS programs, eight also paid for case management services under the waiver and kept track of individual screening determinations. The average acceptance rate of waiver applicants in these eight programs during Federal FY 1985 was 40 percent, compared to an average acceptance rate of 59 percent for all other waiver programs. While other factors could be at work here, e.g. single versus multiple level screening processes, it would appear that the presence of case managers is associated with higher refusal rates and, perhaps, more accurate screening of waiver applicants.

Quality Assurance

In approaching the difficult and elusive topic of quality assurance, the survey sought to describe the type of models States had in place to perform quality review activities. It is beyond the scope of this report to judge how well the States are actually performing these activities.

Quality assurance activities conducted by case managers have been alluded to above, and include functions "H": monitoring quality of care provided, and "J": assessing clients progress and continued appropriateness in the waiver program (see Exhibit 3-20). In addition, the survey asked States about the presence or absence of independent review of certain aspects of the provision of waiver services. By "independent review" is meant independent of the case manager or provider of services.

Exhibit 3-21 demonstrates that two-thirds of the States perform independent review to determine if care plans continue to meet waiver client needs, and if clients actually receive the services in the care plan. However, only one-third of the programs extend quality review to include the direct observation of care provided in the home, and an assessment of client outcome.

EXHIBIT 3-21

STATE APPROACHES TO QUALITY ASSURANCE

N = 39 PROGRAMS

QUALITY ASSURANCE ACTIVITY a/	NUMBER OF PROGRAMS	AS PERCENT OF ALL A/D WAIVERS
1. Independent review determines if care plan continues to meet needs.	26	65%
2. Independent review determines if clients actually receive services in care plan.	24	60%
3. Provision of care directly observed.	14	36%
4. Client outcomes assessed by independent reviewer.	15	38%
5. None.	5	13%

a/ Activities refer to "independent review," i.e. independent of provider and case manager, of certain aspects of provision of waiver services.

Source: La Jolla Waiver Survey (1985)

The survey indicates that nurses play the main role in conducting the independent review activities described in Exhibit 3-21, either alone or teamed with a social worker. Social workers also bear a significant responsibility for quality review. The involvement of physicians in independent quality review is minimal, with only three waiver programs reporting a physician presence on the review staff. No State reported having a nurse practitioner on the review team, and only one indicated that a psychologist was involved.

Face-to-face client assessment is not a major component of independent review. Only three A/D waiver programs reported that this method was their sole data source, and 16 others said it was utilized in performing at least one of the four review activities. Most often States relied upon reference to client records and/or a central data system to make their determinations.

In performing independent quality review States most often relied upon a sample of waiver clients, except when the activity was to assess whether the care plan continued to meet client needs. In that case, States' review tended to cover all waiver clients and not merely a sample. States reported on the survey that independent quality review activities were most often performed on an annual basis.

Finally, States were asked to list the most significant problems which they have found in ensuring the quality of care provided to clients under the waiver. Just under half of the waiver programs reported having problems with quality of care. For those that did, the nature of the difficulties fell into two broad categories: (1) Provider shortages, rapid turnover and/or poor preparation; and (2) Care plans which were inadequately drawn up and/or not fully implemented. In addition, some miscellaneous quality problems were described such as deteriorating home environment, inadequate waiver lead agency staffing, and failure of physicians to complete medical evaluations on a timely basis. While some States were taking actions to address the problems outlined above, several States reported they were satisfied with the quality control mechanisms in place (e.g., New Jersey, New York and Virginia). Others specifically praised the role of the case manager in furthering quality review through timely monitoring of the care provided (e.g., Minnesota).

CHAPTER FOUR
WAIVER PROGRAMS SERVING THE DEVELOPMENTALLY DISABLED AND CHRONICALLY MENTALLY ILL

This chapter presents findings from the La Jolla Waiver Survey of Section 2176 waiver programs which serve the developmentally disabled and chronically mentally ill. In Federal FY 1985, 33 States had 41 separate approved waivers for the developmentally disabled or chronically mentally ill. Four of these waiver programs ended their three-year terms in FY 1985 and were not renewed: three waivers for the developmentally disabled in Louisiana, Iowa and West Virginia, and one waiver for the chronically mentally ill in Colorado. The data presented in this chapter include information on these four programs, but generally exclude information about four other waiver programs which had been approved but which had not yet been implemented at the time of the survey: two in Pennsylvania, one in Texas, and one in Oklahoma. Sample sizes also vary in the presented findings, depending upon the response rate to individual questions on the survey instrument.

TARGETING OF DD/CMI WAIVERS

The major target group in waiver programs serving the developmentally disabled and chronically mentally ill is mentally retarded persons over the age of 21, as shown in Exhibit 4-1. Thirty-seven of the 41 DD/CMI waiver waivers serve mentally retarded adults. Twenty-six of those waivers also serve mentally retarded children. Fourteen States also provided waiver services to other developmentally disabled populations, such as persons with cerebral palsy, epilepsy, autism, and other related conditions. Four States--Colorado, Rhode Island, Oregon and Vermont--had waiver programs which served the chronically mentally ill.

Eligibility for waiver program entry

A primary issue in targeting waiver services for the developmentally disabled is whether a waiver is used primarily to deinstitutionalize clients from ICF-MR certified facilities, or whether it is used to divert clients already living in the

Exhibit 4-1

Target Groups for Waivers Serving the Developmentally Disabled and Chronically Mentally Ill

n = 41

State	Mentally Retarded Adults	Mentally Retarded Children (Under 21)	Other Developmentally Disabled: Cerebral Palsy	Other Developmentally Disabled: Epilepsy	Other Developmentally Disabled: Autism	Other Developmentally Disabled: Other DD	Other Developmentally Disabled: Not Specified	Chronically Mentally Ill
AL	x							
CA	x	x	x	x	x			
CO								x
CO	x	x	x		x			
DE	x	x						
FL	x	x						
HI	x	x						
ID	x	x	x					
IL	x		x	x	x			
IA	x							
KA	x							
KY	x	x				x		
LA	x							
ME	x	x						
MD	x	x						
MA	x							
MN	x	x					x	
MT	x	x				x		
NV	x	x						
NH	x		x		x			
NJ	x	x						
NM	x	x				x		
NC	x	x					x	
ND	x	x						
OK	x	x						
OR	x	x						
OR								x
PA	x							
PA	x							
PA	x							
PA	x	x						
RI								x
RI	x	x						
SD	x	x						
TX	x	x						
UT	x							
VT	x	x						
VT					x			x
WA	x	x					x	
WV	x	x				x		
WI	x	x	x	x	x	x		
	37	26	6	3	6	5	3	4

Source: La Jolla Waiver Survey (1985). Includes all waivers which were operational at some time during FY 1985 (October 1984 through September 1985).

community from institutional placement. As shown in Exhibit 4-2, in almost all DD waiver programs, persons being deinstitutionalized from public ICF-MRs were eligible for the waiver. Persons in privately-operated ICF-MRs or in other institutional settings were less likely to be eligible for waiver services. Only five of the 33 DD waivers, however, limited eligibility to the deinstitutionalized population. In the remaining 28 DD waivers, persons in the community, but at-risk of placement in an ICF-MR, were also eligible for waiver services.

The survey also asked States to indicate which target groups received priority in gaining admission to the waiver program. As shown in Exhibit 4-3, 20 States indicated that persons being deinstitutionalized from public ICF-MRs had priority over other applicants. Thus, while most States do not limit waiver admissions just to deinstitutionalized clients, many States give priority to such persons in allocating waiver program "slots."

The survey also asked States to provide information on the residential location of waiver clients admitted during FY 1985 immediately prior to their entry into the program. Exhibit 4-4 presents data on actual admissions to DD/CMI waiver programs. Of 29 States which provided these data, 6 (21 percent) admitted clients from institutional settings only, 4 (14 percent) admitted clients only from community settings, while 19 (64 percent) admitted clients from both institutional and non-institutional settings.

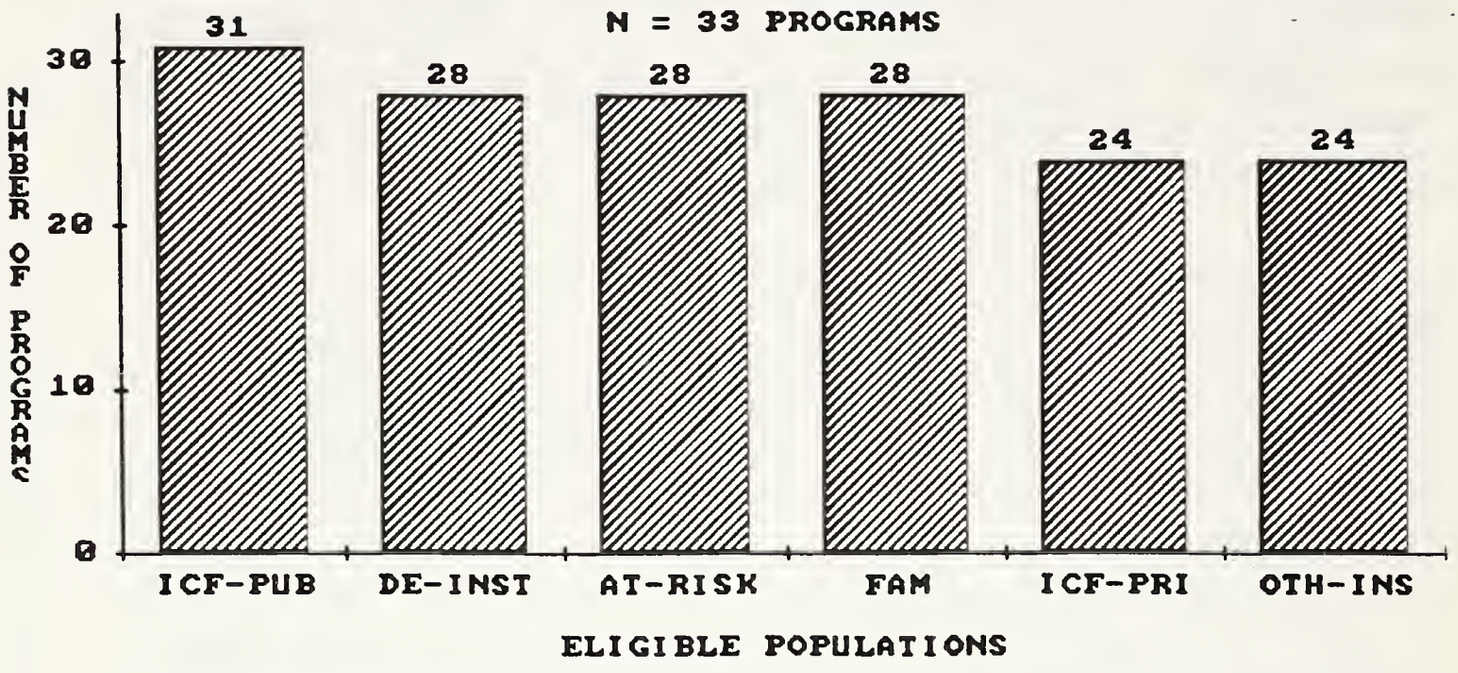
ICF-MR Level of Care Criteria and Waiver Targeting

Federal waiver program regulations require that developmentally disabled waiver recipients meet ICF-MR level of care criteria. States must document that a level of care assessment was conducted on each waiver program applicant prior to receipt of waiver services, and that each waiver recipient met ICF-MR level of care criteria at program entry and at periodic redetermination. States may, at their own discretion, apply criteria which are more restrictive than ICF-MR level of care criteria, in order to enhance the cost-effectiveness of their waiver programs.

The survey, therefore, asked States whether waiver recipients were only required to meet ICF-MR level of care criteria or whether additional criteria were applied in

EXHIBIT 4-2

POPULATIONS ELIGIBLE FOR DD WAIVERS



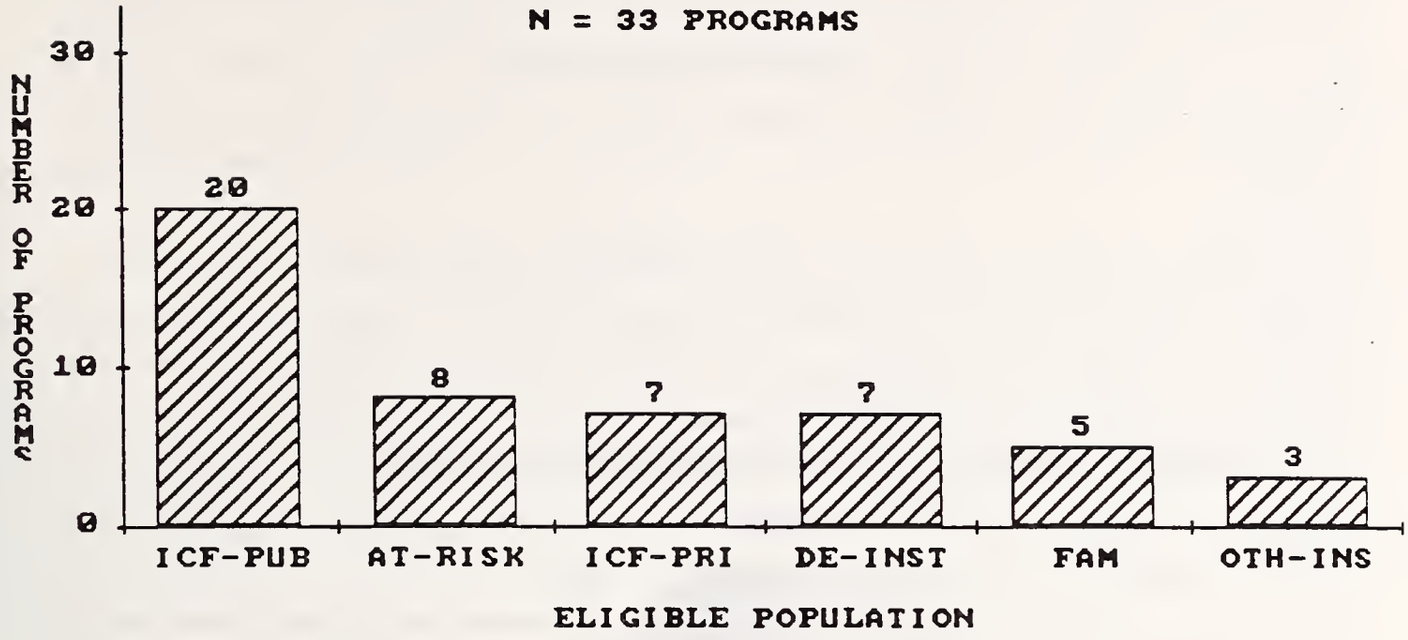
KEY:

ICF-PUB = Public ICF-MR recipients
DE-INST = Deinstitutionalized clients living in the community
AT-RISK = Clients not previously institutionalized but at risk of institutionalization
FAM = Clients living with their own families who are at risk of institutionalization
ICF-PRI = Private ICF-MR recipients
OTH-INS = Persons in other institutional settings

Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-3

SPECIAL TARGET GROUPS FOR ADMISSION TO DD WAIVER PROGRAMS



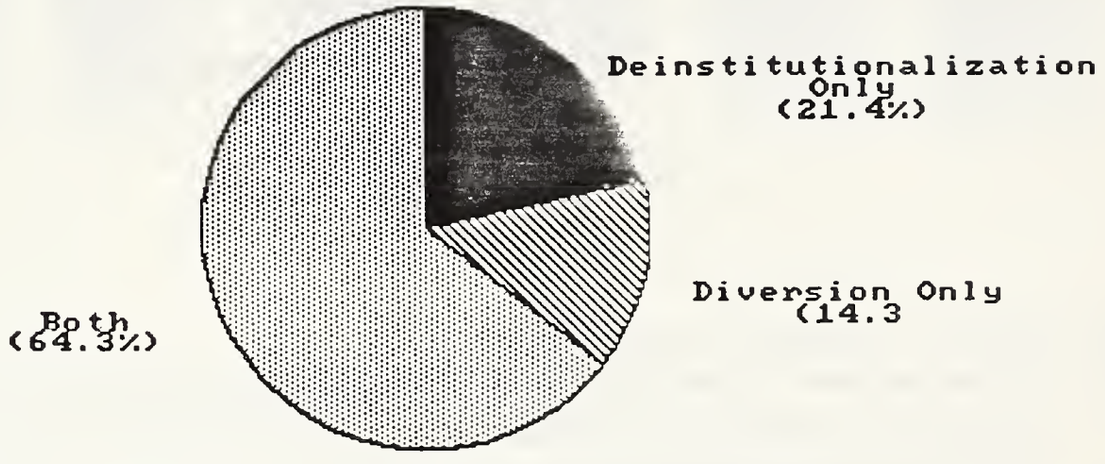
KEY:

ICF-PUB = Public ICF-MR recipients
AT-RISK = Clients not previously institutionalized but at risk of institutionalization
ICF-PRI = Private ICF-MR recipients
DE-INST = Deinstitutionalized clients living in the community
FAM = Clients living with their own families who are at risk of institutionalization
OTH-INS = Persons in other institutional settings

Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-4
SUMMARY TARGET GROUPS FOR DD/CMI WAIVERS

N = 28 PROGRAMS



Source: La Jolla Waiver Survey (1985)

targeting waiver services. In 17 of 31 (55 percent) DD waivers, only ICF-MR criteria were used (Exhibit 4-5). The remaining 14 programs applied additional criteria, above and beyond ICF-MR level of care criteria. Most common were criteria which restricted waiver entry to clients coming from specific types of facilities, and age criteria.

Only a few States applied additional criteria to improve targeting efficiency in their waiver programs. In Rhode Island, in addition to meeting ICF-MR level of care criteria, program applicants living in the community were required to either: a) be severely or profoundly retarded; b) be living with a single parent or with parents over the age of 60; or c) have been previously deinstitutionalized from an ICF-MR. In Montana, in order for diverted clients to be admitted to the waiver, there had to be historical documentation of repeated attempts at out-of-home placement prior to application for waiver services. These types of targeting criteria were the exception, not the rule. Several States which indicated that they applied additional targeting criteria beyond ICF-MR level of care criteria cited such nominal criteria as: "must be Medicaid eligible"; and "estimated cost under the waiver must not exceed ICF-MR cost"; and "client must choose waiver care over ICF-MR care."

Since ICF-MR level of care criteria are the primary screening mechanisms employed to determine eligibility for waiver services, the survey asked States to briefly describe the applicable ICF-MR level of care criteria in their respective States. Federal Medicaid regulations on ICF-MR level of care criteria are fairly non-restrictive. Medicaid regulations (42 CFR 440.150 and 442.418) only require that ICF-MR recipients:

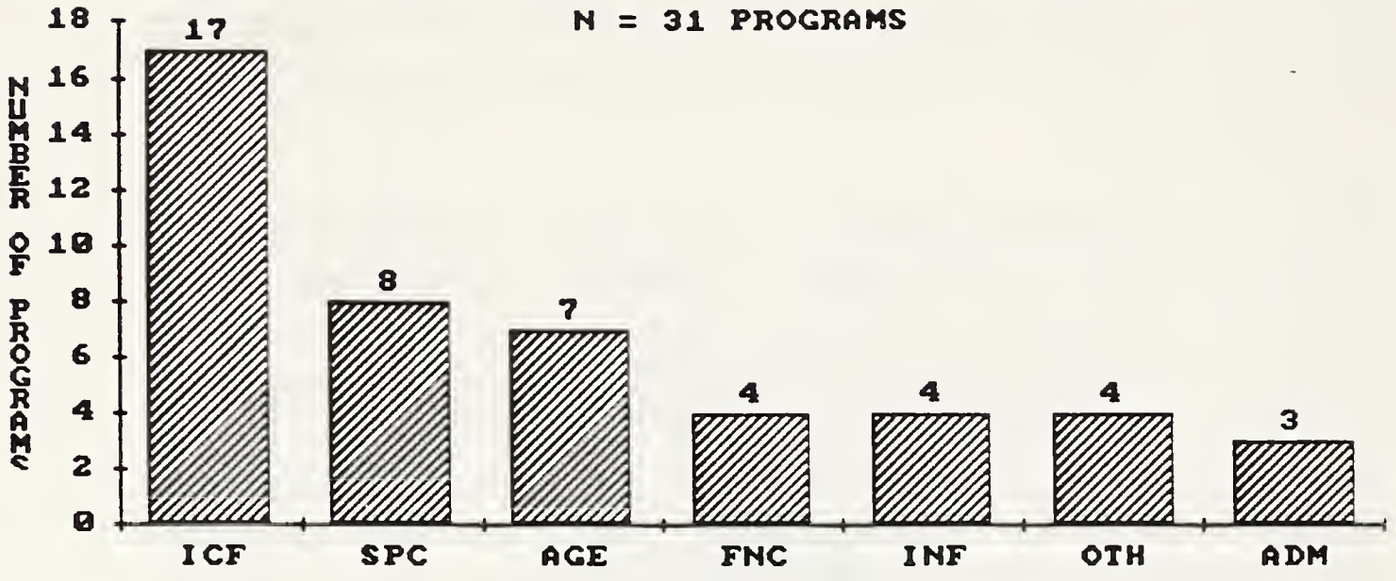
- Have a diagnosis of mental retardation or other developmental disability
- Require services above the level of room and board
- Be in need of active treatment.

States may, at their discretion, establish more restrictive criteria for ICF-MR placement, and these criteria are carried over into the waiver program. Survey responses showed that about half the States simply reiterate the Federal criteria. More restrictive ICF-MR level of care criteria employed in other States include: 1)

EXHIBIT 4-5

TARGETING CRITERIA USED IN DD WAIVER PROGRAMS

N = 31 PROGRAMS



KEY:

ICF = Uses ICF-MR level of care criteria only

SPC = Clients admitted from specific facilities only

AGE = Clients must meet age criteria

FNC = Clients must meet additional funtional and/or developmental criteria

INF = Criteria related to informal care system are applied

OTH = Other targetting criteria

ADM = Clients must have been referred for ICF-MR admission

Source: La Jolla Waiver Survey (1985)

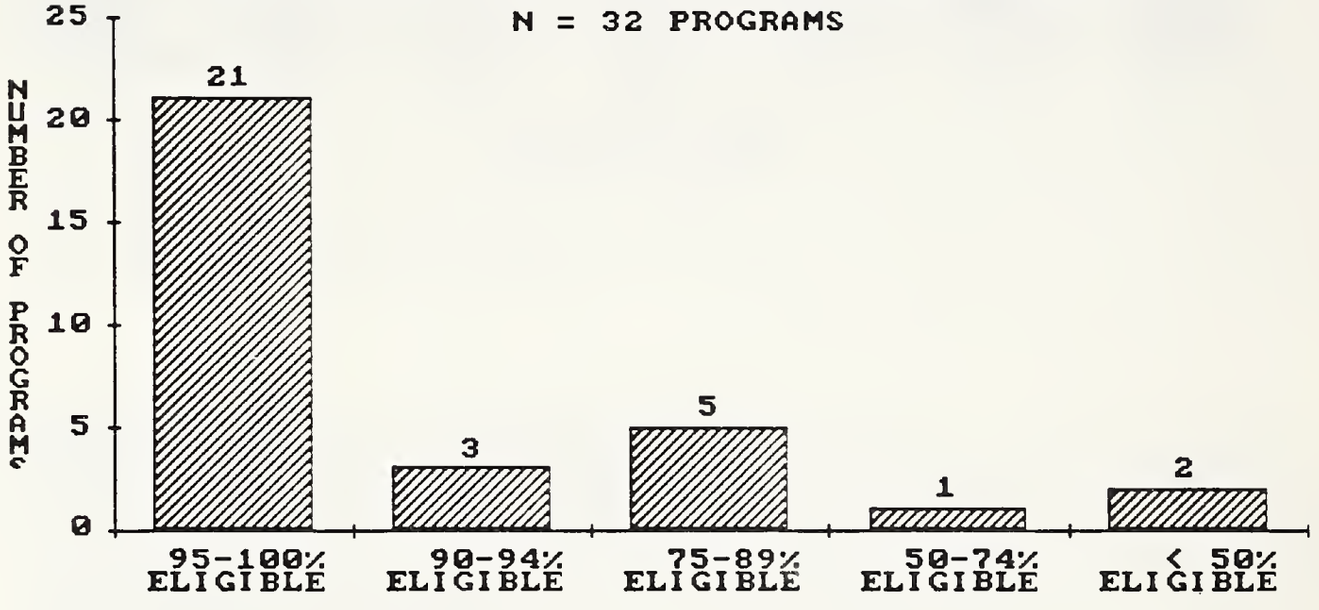
the need for 24-hour supervision; 2) the absence of alternative placement options; and 3) documented deficits in two or more behavioral or self-care skill domains. Some States had established IQ levels as part of their ICF-MR level of care criteria, above which clients could not be admitted unless they demonstrated severe deficits in adaptive behavior. A few States had more complex entrance criteria.

In general, however, State ICF-MR level of care criteria, like the Federal criteria, are quite broad. Consequently, it is not surprising that level of care screening resulted in the exclusion of only a small minority of program applicants. As shown in Exhibit 4-6, 21 of 32 waiver programs (66 percent) reported that 95 percent or more of all assessed clients were determined eligible for the waiver. Over 90 percent of the programs reported that more than 75 percent of assessed clients were determined eligible for the waiver. It should be pointed out that these statistics may also reflect the fact that waiver program administrators know how to screen potential waiver program candidates before level of care assessments are conducted. Program administrators of DD waivers may only be conducting level of care reviews on persons who are likely to meet program entrance criteria, in order to minimize their administrative costs.

Nonetheless, the major conclusion from the survey is that the Federal requirement that DD waiver recipients meet ICF-MR level of care criteria is not, in itself, an effective screen for ensuring the cost-effectiveness of waivers for the developmentally disabled. In most waiver programs, mentally retarded persons who have never been institutionalized and are at low risk of institutionalization could meet the targeting criteria for entry to the waiver program. Although only a small minority of Medicaid-eligible mentally retarded persons are users of ICF-MR care, the majority would meet ICF-MR level of care criteria if they applied. Further, most DD waiver programs do not apply targeting criteria above and beyond formal ICF-MR criteria. Five programs limit waiver program entry to persons who are being deinstitutionalized from ICF-MRs. A few other programs have developed targeting criteria which increase the probability that waiver recipients are at-risk of ICF-MR placement. On the other hand, it would be incorrect to assume that DD waiver programs are not being targeted effectively just because formal targeting criteria are not very restrictive. Effective targeting can only be assessed by

EXHIBIT 4-6

PERCENT OF DD/CMI WAIVER CLIENTS DETERMINED ELIGIBLE FOR WAIVER AFTER LEVEL OF CARE ASSESSMENT



Source: La Jolla Waiver Survey (1985)

knowing the characteristics of clients who are actually served under the waiver. The next section will consider these client characteristics.

Where Waiver Clients Come From

The La Jolla Waiver Survey asked States to provide information on the residential location of waiver program clients immediately prior to their entry into the waiver. These data are provided in Exhibits 4-7 and 4-8. Among recipients who entered the program in FY 1985, the most common entry point was from an ICF-MR, either a publicly-operated or privately-operated facility. One-third of all waiver clients entered the program from an ICF-MR or other institutional setting, such as a nursing home, hospital, or non-certified State facility. This percentage is significantly higher than reported on the First Annual Survey of Section 2176 waiver programs, in which only 15 percent of developmentally disabled waiver clients were reported to enter the waiver directly from ICF-MRs.

Of the remaining new enrollees, an approximately equal number entered the program while living at home (28.0 percent) and in group residences (27.7 percent). Another 6.9 percent lived in private residential settings other than with their parents. States did not know the prior residential location of 7.6 percent of new waiver enrollees. It is important to note that these data only reflect responses from 27 of the 41 programs that were able to report the prior residential location of at least part of their waiver population. Ten programs either enrolled no waiver clients in FY 1985, or were not able to provide these data.

CLIENT CHARACTERISTICS AND ENROLLMENT PATTERNS

Characteristics of DD Waiver Clients and ICF-MR Recipients

The survey asked States to provide information on the characteristics of waiver recipients who were enrolled in the waiver program on September 30, 1985. Exhibits 4-9 through 4-14 present information on the characteristics of developmentally disabled and chronically mentally ill waiver clients, and their enrollment patterns. As shown in Exhibit 4-9, most developmentally disabled waiver clients are young adults, between the ages of 22 and 39. Fifty-five percent are

EXHIBIT 4-7

ENTRY POINTS FOR WAIVER CLIENTS
ENROLLED IN FY 1985
N = 27 PROGRAMS

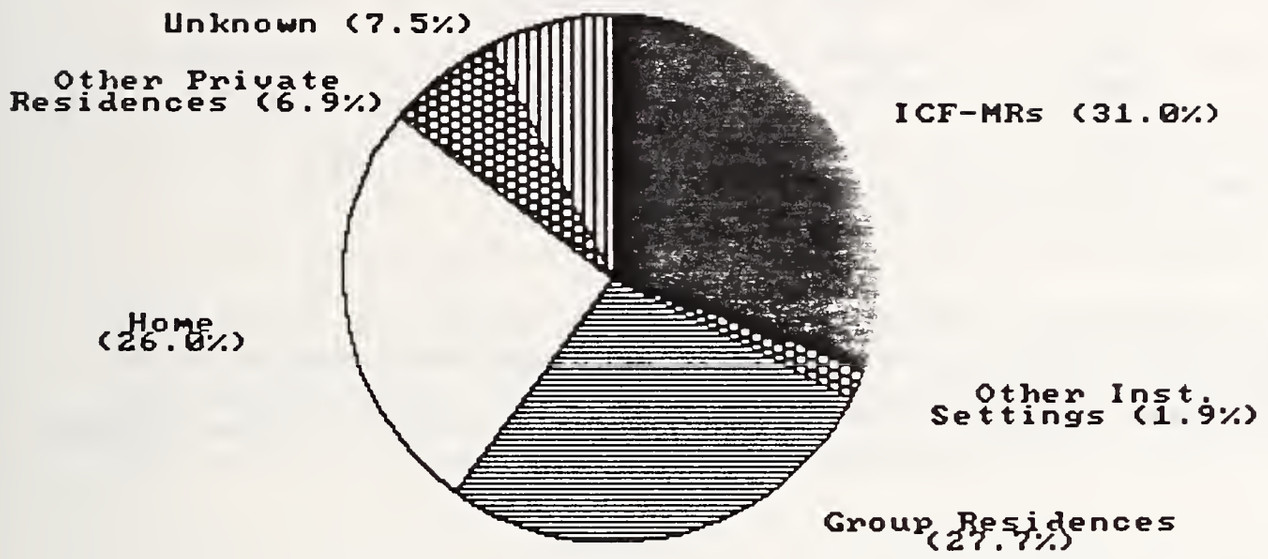
STATE	--INSTITUTIONAL-- PUBLIC ICF-MR	PRIVATE ICF-MR	OTHER INST.	--GROUP RESIDENCE-- GROUP HOME	APT. PROGRAM	FOSTER CARE	OTHER GROUP	--PRIVATE RESIDENCE-- LIVING W/PARENTS	OTHER	DON'T KNOW	TOTAL
AL	2	0	5	30	5	25	25	59	20	9	180
CA	168	0	0	78	0	0	0	0	0	0	246
CO	0	133	0	0	0	0	0	0	0	143	276
CO	0	0	1	67	0	0	85	35	117	4	309
DE	21	0	0	2	0	0	0	0	1	0	24
HI	4	0	0	0	0	0	0	0	0	0	4
ID	2	0	1	0	0	0	0	23	0	7	33
IL	128	37	0	0	0	0	0	0	0	90	255
KY	10	9	6	11	11	2	4	75	4	0	132
MD	229	0	0	0	0	0	0	0	0	0	229
ME	35	31	9	25	0	121	1	84	6	0	312
MN	19	53	19	0	0	20	0	107	0	0	218
MT	20	52	3	65	0	20	0	30	0	0	190
NC	11	0	2	13	0	7	3	20	3	0	59
ND	0	0	0	0	0	0	0	0	0	51	51
NH	66	0	0	0	0	0	0	40	9	0	115
NJ	1	0	22	163	33	168	67	369	0	0	823
NM	4	0	1	17	0	4	0	20	0	0	46
NV	38	0	0	8	0	0	0	16	0	0	62
PA	75	0	0	0	0	0	0	0	0	0	75
PA	50	0	0	0	0	0	0	0	0	0	50
RI	2	8	0	0	7	6	0	82	13	0	118
RI-CMI	0	0	1	29	2	0	0	97	0	0	129
SD	14	29	10	38	3	11	0	44	4	13	166
VT	0	1	2	3	0	0	0	3	0	0	9
WI	40	0	0	0	0	0	0	0	0	0	40
WV	26	0	0	0	0	0	0	0	0	0	26
TOTAL:	965	352	82	546	61	384	185	1101	177	317	4170

Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-8

ENROLLEE POINTS OF ENTRY FOR
DD/CMI WAIVER CLIENTS

N = 27 PROGRAMS



Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-9
DISTRIBUTION OF DD WAIVER CLIENTS BY AGE AND SEX; ICF-MR RECIPIENTS BY AGE
N = 25 PROGRAMS

	--- DD WAIVER CLIENTS ---			ICF-MR RECIPIENTS IN WAIVER STATES
AGE	MALE	FEMALE	TOTAL	TOTAL
0 - 14	5.9 %	4.3 %	10.2 %	6.9%
15 - 21	7.0 %	5.4 %	12.4 %	14.7%
22 - 39	31.4 %	26.0 %	57.4 %	50.0%
40 - 64	9.0 %	9.4 %	18.3 %	23.9%*
65+	0.9 %	0.9 %	1.7 %	4.4%**
TOTALS:	54.1	45.9	100%	100.0%

* 40 - 62 years for ICF-MR recipients.
** 63 years and over for ICF-MR recipients.

Source: La Jolla Waiver Survey (1985) and 1982 survey of residential care facilities for the mentally retarded conducted by the Center for Residential and Community Services, University of Minnesota. Data on ICF-MR recipients are only for those States which provided age and sex data on the survey.

male. This distribution by sex is reflective of the overall mentally retarded population. There is a higher incidence of mental retardation among males than females.

Exhibit 4-9 shows that in comparison to the ICF-MR population in waiver States, waiver recipients are somewhat younger. Eighty percent of waiver recipients were under the age of 40, compared to 72 percent of the ICF-MR population.

By level of retardation, waiver recipients differed significantly from the ICF-MR population in waiver States, as surveyed in 1982 (Exhibit 4-10). Mildly and moderately retarded persons comprised only 21.8 percent of the ICF-MR population, but 53.0 percent of the waiver population. Severely retarded persons comprised a somewhat higher proportion of waiver recipients (30.2 percent) than ICF-MR recipients (25.5 percent). Profoundly retarded persons comprised 52.6 percent of the ICF-MR population in 1982, and 16.8 percent of the waiver population in 1985.

Overall, the distribution of waiver recipients by level of retardation more closely resembles the characteristics of mentally retarded persons in residential facilities which were not certified as ICF-MRs in 1982 than they resemble the characteristics of ICF-MR recipients. However, the data indicate that waiver recipients were more severely retarded than persons in non-ICF-MR facilities.

Exhibit 4-11 compares waiver recipients and ICF-MR recipients in four functional activities of daily living: toileting, ambulation, dressing, and verbal communication. On these criteria as well, waiver recipients were, on average, not as impaired as ICF-MR recipients. The prevalence of deficits in each functional area was generally four times higher in the ICF-MR population than in the waiver population.

While these data on the characteristics of waiver recipients and ICF-MR recipients suggest that the waiver population is, on average, not as impaired as the ICF-MR population, this does not necessarily mean that DD waiver programs are not substituting for ICF-MR care. The objective of the waiver is to serve clients who are at-risk of institutionalization, but who can be served equally well in non-ICF-MR settings. Thus, of the total population in ICF-MRs, or at-risk of ICF-MR placement, one would expect the waiver to focus on the relatively

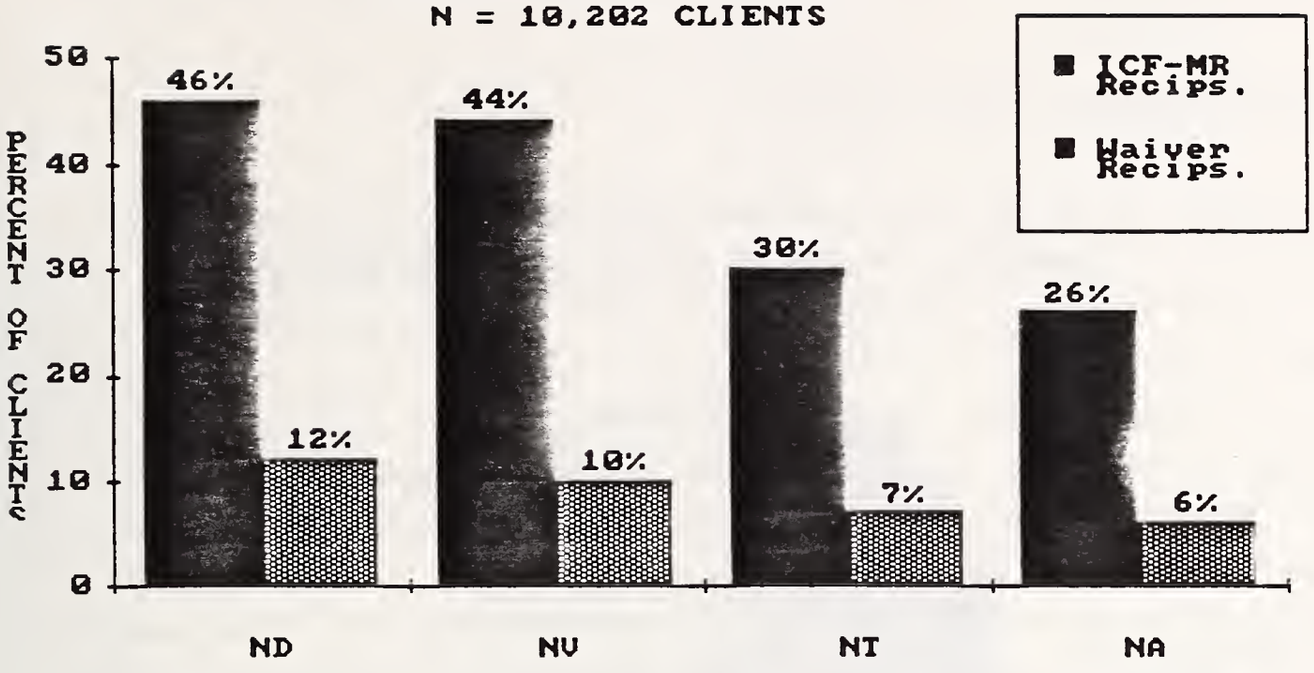
EXHIBIT 4-10

MENTALLY RETARDED WAIVER RECIPIENTS
BY LEVEL OF RETARDATION COMPARED TO
ICF-MR RECIPIENTS AND RESIDENTS OF
NON-ICF-MR FACILITIES
N = 20 PROGRAMS

LEVEL OF RETARDATION	WAIVER RECIPIENTS	ICF-MR RECIPIENTS (WAIVER STATES)	NON-ICF-MR RECIPIENTS ALL STATES
MILD	21.8 %	8.0%	
			64.8%
MODERATE	31.2 %	13.8%	
SEVERE	30.2 %	25.5%	22.0%
PROFOUND	16.8 %	52.6%	13.2%
TOTALS:	100.0%	100.0%	100.0%

Source: La Jolla Waiver Survey (1985) and 1982 survey of residential care facilities for the mentally retarded conducted by the Center for Residential and Community Services, University of Minnesota.

EXHIBIT 4-11
FUNCTIONAL IMPAIRMENTS
N = 10,202 CLIENTS



KEY:

ND = Needs assistance in dressing
NV = Non-verbal
NT = Needs assistance in toileting
NA = Non-ambulatory

Sources: La Jolla Waiver Survey (1985) and the National Survey of Residential Care Facilities for the Mentally Retarded, University of Minnesota.

higher-functioning clients for whom ICF-MR care is not the most cost-effective care setting. Viewed positively, the data in Exhibits 4-9 through 4-11 indicate that there is considerable overlap between the waiver population and the ICF-MR population, and that almost half of all waiver clients are either severely or profoundly retarded.

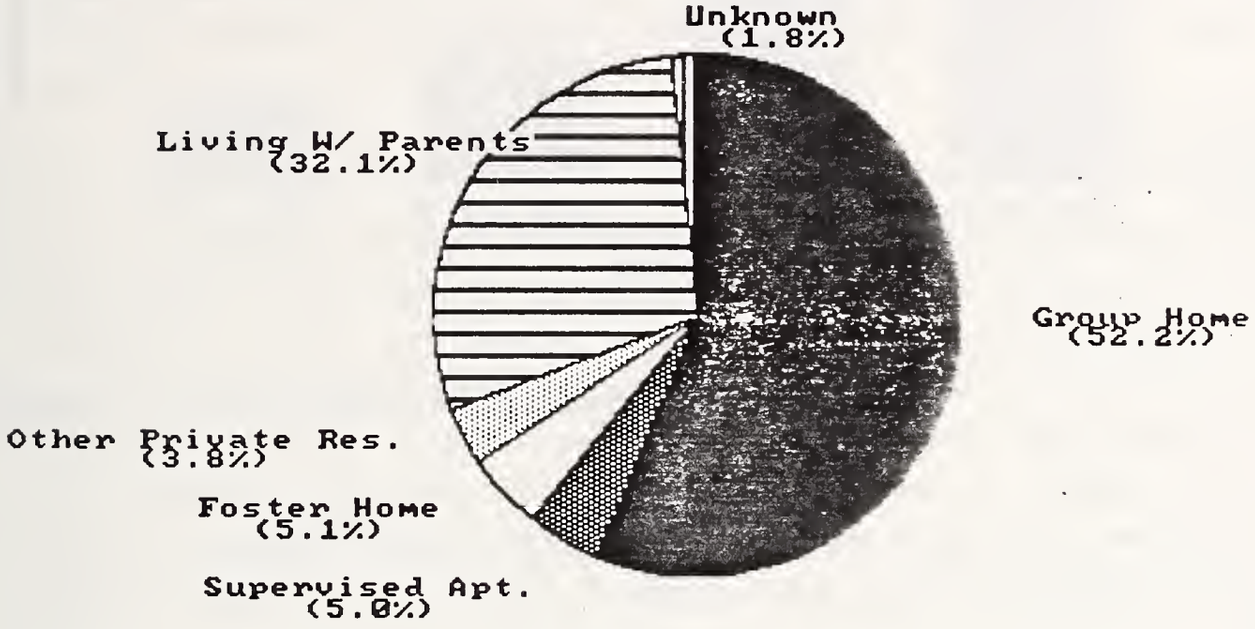
Residential Placements of Waiver Clients

About half of all DD/CMI waiver clients (52.2 percent) live in group homes (Exhibit 4-12). These are usually staffed single-family dwellings housing between 3 and 12 clients. Residential program staff may live in the home, or rotate in shifts. Clients are generally out of the residence for at least part of the day during the regular workweek, participating in a developmental training program, sheltered workshop, or transitional employment program, depending on their skill level. The cost of residential program staff is often covered under the waiver, but the actual cost of room and board is not an allowable waiver service. Room and board are generally paid for by clients' SSI/SSP income and general State funds. These group homes are generally not as intensively staffed as small scale ICF-MRs, and life and safety codes are generally not as stringent as ICF-MR standards.

Another third of waiver clients live at home with their parents. For these clients, the waiver is used to pay for day programs, transportation services, respite care, and other services, but not residential services. It is important to remember that under the optional waiver of deeming regulations, States can extend Medicaid eligibility to persons living at home with their parents who, due to the deeming of parental income under usual Medicaid eligibility rules, would otherwise not be eligible for medical assistance. However, the proportion of waiver clients living at home with parents is significantly higher than the percentage of clients which States reported have been made eligible for Medicaid under this special provision, suggesting that most waiver clients living at home are in Medicaid-eligible households.

A relatively small percentage of clients lived in either foster homes (5.1 percent), supervised apartment programs (5.0 percent) or in other private residences (3.8 percent).

EXHIBIT 4-12
RESIDENTIAL PLACEMENT OF DD/CMI CLIENTS
N = 20,048 CLIENTS



Source: La Jolla Waiver Survey (1985)

Lengths of Enrollment Among DD/CMI Waiver Clients

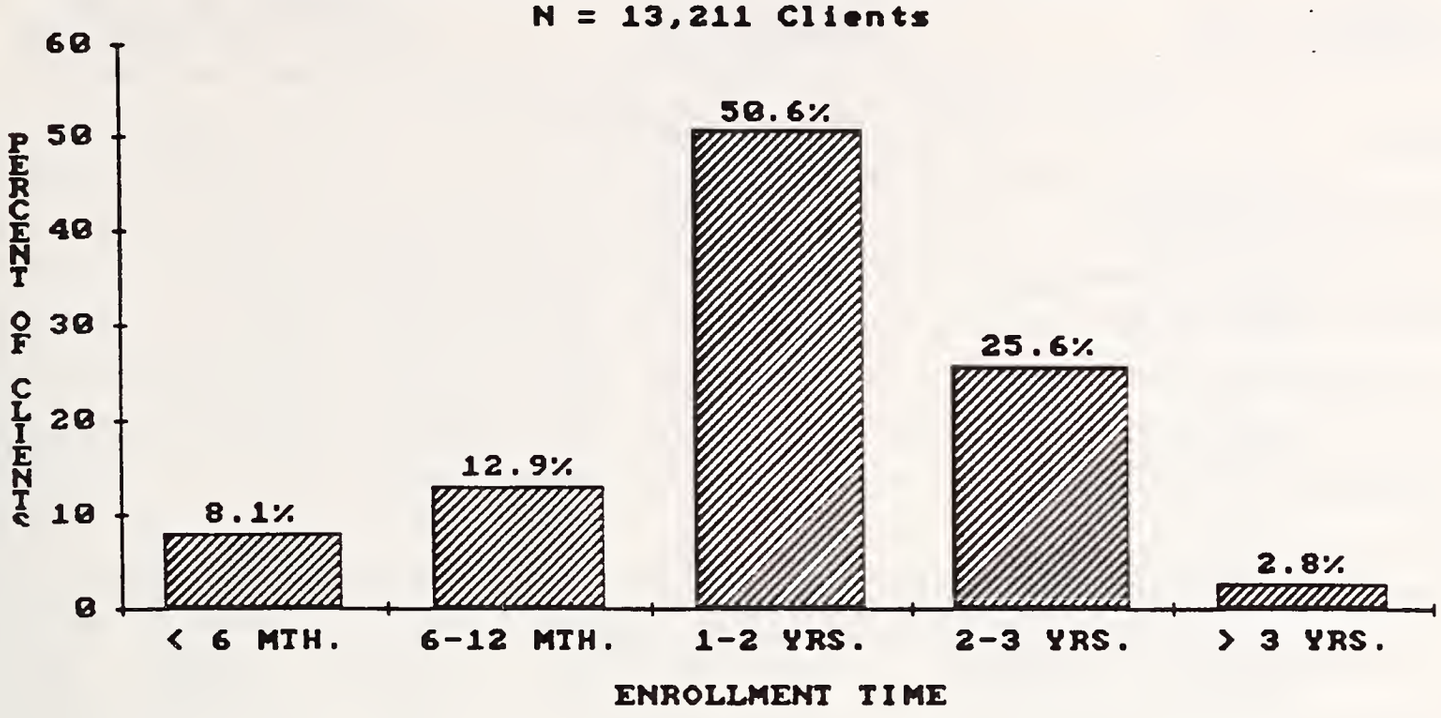
As of March 1986, most DD/CMI waiver clients have been in the program between one and three years (Exhibit 4-13). Lengths of enrollment depend upon when new waivers become approved and when existing waivers terminate, as well as client turnover rates, so that Exhibit 4-13 is more illustrative of "program build-up" than of client turnover. The exhibit shows that most of the growth in the DD/CMI waiver population occurred in FYs 1983 and 1984; enrollment of new waiver clients declined significantly in FY 1985. This reflects both the fact that many existing waivers had already reached their projected estimates of waiver program enrollment, and were prevented from enrolling new clients, and the fact that there were significantly fewer new waivers approved in FY 1985 than in the previous two years.

Reasons for Disenrollment

Other than disenrollment forced by the termination of waiver programs, there is relatively low turnover in DD/CMI waiver programs. In the 30 States which were able to report disenrollment data, there was a turnover rate of only 12 percent among DD/CMI waiver clients in FY 1985. Further, many disenrollments were for special circumstances. For example, Nevada was forced to disenroll 270 clients when HCFA required it to change its eligibility requirements for the waiver. In transition from its first three-year waiver, to its renewed waiver, Vermont was also required to disenroll its entire adult chronically mentally ill population of 100 clients.

Of a total of 1,770 disenrollments in 1985, only 18 percent were due to ICF-MR placement, 5 percent were due to deaths, and 9 percent due to clients not meeting level of care criteria at re-assessment (Exhibit 4-14). This is in marked contrast to waivers for the aged and disabled, in which 80 percent of disenrollees left the program for one of these three reasons (see Chapter Three). This suggests that disenrollment rates in DD/CMI waiver programs would be even lower in a "steady state" program which was not affected by administrative actions or renewal provisions.

EXHIBIT 4-13
LENGTH OF ENROLLMENT FOR DD/CMI CLIENTS
N = 13,211 Clients



Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-14

PROGRAM DISENROLLMENTS a/

N = 31

REASONS FOR DISENROLLMENT	NUMBER OF DISENROLLEES	PERCENT OF TOTAL DD/CMI DISENROLLEES
DEATH	85	4.8 %
ICF-MR PLACEMENT	284	16 %
PLACEMENT IN NON-MED. CERT. INSTITUTION	2	0.1 %
PLACEMENT IN ICF/SNF	28	1.6 %
CLIENT TRANSFERRED TO NON-WAIVER PROVIDER	242	14 %
DID NOT MEET LEVEL OF CARE CRITERIA AT RE-ASSESS.	167	9.4 %
LOST MEDICAID ELIGIBILITY	157	8.9 %
MOVED FROM SERVICE AREA	46	2.6 %
WAIVER FORMULA LIMITS FORCED DISENROLLMENT	270	15 %
EXCEEDED COST CAP	5	0.3 %
PROGRAM LOST TRACK OF CLIENT	19	1.1 %
VOLUNTARY DISENROLLMENT	69	3.9 %
OTHER	316	17.9 %
DON'T KNOW	80	4.5 %
Total:	1770	100.0 %

a/ For disenrollments in FY 1985.

Source: La Jolla Waiver Survey (1985)

SERVICE UTILIZATION/COST ISSUES

Use of Waiver Services

The three services used most frequently by DD/CMI clients are "Case Management", "Habilitation" and "Residential Services", as shown in Exhibit 4-15. "Habilitation" is really a generic term for a wide range of developmental training services. Habilitation often means all the services provided in a day treatment program for developmentally disabled persons. In good programs, the actual services provided are highly individualized to the level and needs of clients. Sixty percent of DD/CMI recipients received "Case Management" as a formal waiver service; although this amount increases to 92 percent once programs which pay for these services out of Medicaid administrative funds are added in.

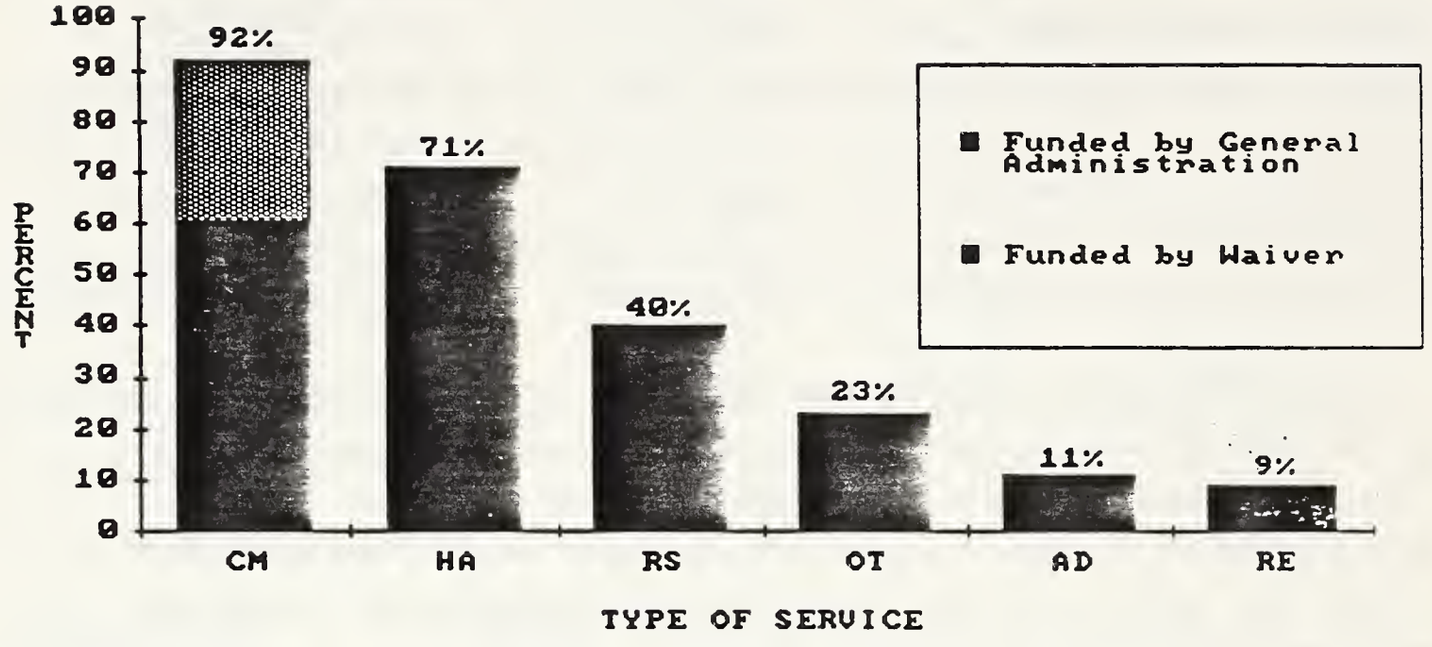
Exhibit 4-16 presents data on FY 1985 expenditures for waiver services from 31 of the 40 DD/CMI waiver programs which were operational at some time during the year. These States reported a total of $161,273,676 in expenditures for waiver services in FY 1985. Almost four-fifths of expenditures were for "Residential" and "Habilitation" services. "Case Management", "Respite", "Adult Day Care" and "Other" waiver services comprised the remaining 20 percent of expenditures.

Average Cost Per Day of Waiver Services and ICF-MR Care

As in all 2176 waiver programs, States are required to demonstrate that developmentally disabled waiver recipients, on average, can be served at a lower cost in the community than in an ICF-MR. For those States which were able to provide both FY 1985 expenditure data for waiver services and the total number of days of waiver coverage provided in FY 1985, Exhibit 4-17 presents the average cost per day of waiver care compared to the average cost of ICF-MR care, as provided on FY 1985 HCFA 2082 reports.

The average cost per day of waiver care ranged widely, from $17.94 per day in Louisiana to $141.05 per day in one of Pennsylvania's two DD waivers. The average daily cost of waiver care also ranged from 16 percent of the average daily cost of ICF-MR care in Nevada, to 118 percent of average ICF-MR costs in Pennsylvania.

EXHIBIT 4-15
PERCENT OF CLIENTS RECEIVING SERVICE[a/]



KEY:

CM = Case Management
HA = Habilitation
RS = Residential Services
OT = Other
AD = Adult Day Care
RE = Respite

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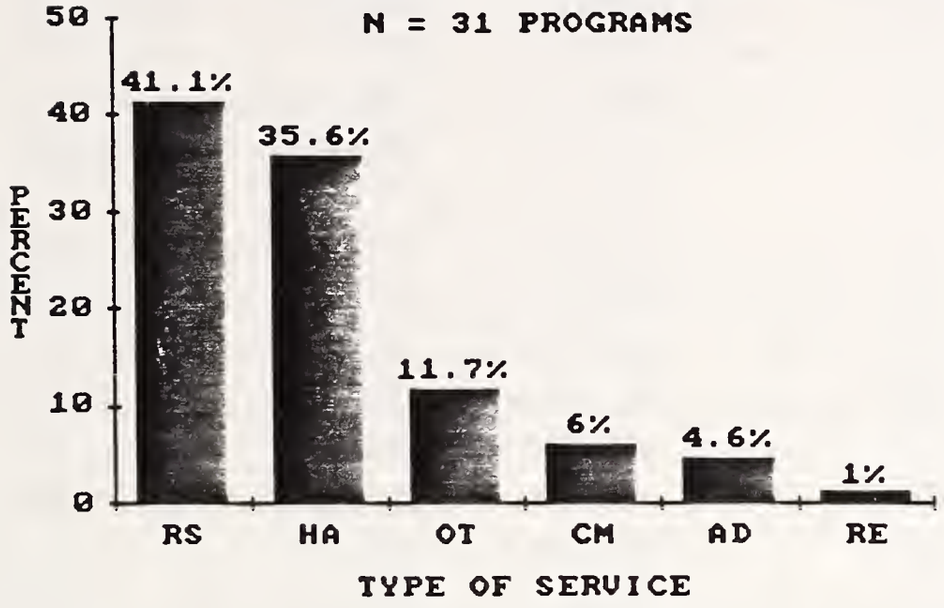
a/ Utilization data are for each waiver service delivered during the period 10/1/84 - 9/30/85.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-16

DISTRIBUTION OF DD/CMI EXPENDITURES BY TYPE OF SERVICE a/

N = 31 PROGRAMS



Total DD/CMI 1985 Expenditures = $161,273,676

Residential	=	$66,307,884
Habilitation	=	$57,443,045
Other	=	$18,888,130
Case Management	=	$ 9,680,520
Adult Day Care	=	$ 7,403,902
Respite	=	$ 1,550,195

a/ Expediture data are for each waiver service delivered during the period 10/1/84 - 9/30/85. For several States the timeframe reported is slightly different. The following States were unable to respond: Colorado (1 of 2 programs), Florida, Massachusetts, Minnesota, and Vermont.

Source: La Jolla Waiver Survey (1985)

EXHIBIT 4-17

COST OF WAIVER DAY VERSUS ICF-MR DAY

N = 21

DD WAIVER PROGRAM	WAIVER COST/DAY	ICF-MR COST/DAY	BREAK-EVEN RATIO
CA	$22.17	$92.28	24%
CO	$40.38	$86.49	47%
DE	$18.18	$65.29	28%
HI	$24.66	$104.02	24%
ID	$33.87	$87.72	39%
IL	$66.74	$77.43	86%
KY	$60.92	$91.33	67%
LA	$17.94	$70.58	25%
MD	$99.00	$90.91	109%
ME	$38.29	$97.83	39%
MT	$69.38	$94.35	74%
ND	$25.31	$97.50	26%
NJ	$27.47	$122.25	22%
NM	$26.20	$86.17	30%
NV	$21.43	$131.88	16%
PA (1)	$86.17	$119.37	72%
PA (2)	$141.05	$119.37	118%
SD	$26.49	$63.92	41%
WA	$34.49	$78.88	44%
WI	$45.47	$91.17	50%
WV	$20.34	$101.83	20%
AVERAGE:	$45.05	$93.84	48%

Sources: La Jolla Waiver Survey (1985) and HCFA 2082 data. All data are for FY1985.

Three States--Pennsylvania, Maryland, and Wisconsin--reported daily waiver costs in excess of average ICF-MR costs. This does not necessarily mean that these programs are not cost-effective. All three of these States limited waiver program admissions to clients being deinstitutionalized from their State-operated institutions. The average daily costs of care in these State institutions is generally higher than the average daily cost of all ICF-MRs in these States, public and private. In general, with the exception of West Virginia, those States which took a greater percentage of their waiver population directly from ICF-MRs reported significantly higher costs per day of waiver coverage.

Actual ICF-MR costs per day may be also higher than as reported on HCFA 2082s for a variety of reasons, including lagged claims for ICF-MR services, since HCFA 2082 are by date of payment, not date of service. Maryland stated that actual ICF-MR costs per day were higher than $90.91, as reported on the 2082.

Use of Non-waiver Services by Waiver Clients

Developmentally disabled and chronically mentally ill waiver clients receive a considerable amount of supplemental services beyond what is provided through the waiver program itself or financed through SSI income, as shown in Exhibit 4-18. The most common additional source of assistance was State supplements to SSI. In most States, DD/CMI clients who reside in State-funded residential programs pay for their room and board from their SSI/SSP checks, after deducting an allowance for their personal needs.

Many States provide residential services and/or habilitation services for waiver clients through State general funds rather than under the waiver. Some States appear to use the waiver to fund residential services, but not day habilitation programs or conversely, finance day programs under the waiver, but not residential services. Thus, it appears that in many cases the waiver is being used to fund only a portion of the total package of services provided to waiver clients. It is not clear why some States have elected not to finance all eligible home and community-based services to waiver clients under the auspices of the waiver.

EXHIBIT 4-18

PERCENT OF CLIENTS RECEIVING
SUPPLEMENTARY SERVICES
N = 19

TYPE OF SERVICE	AVERAGE PERCENT OF CLIENTS RECEIVING SERVICE
Medicaid home health service not included in waiver.	2.8%
State/Federally funded vocational training services.	10.3%
Services funded through Social Services Block Grant.	7.2%
State supplements to SSI.	61.4%
State-funded residential care (excluding SSI/SSP).	33.9%
Federal housing subsidies (e.g., Section 8).	7.3%
State-funded habilitation/developmental training services.	18.6%
Federal/State/local special education services.	12.9%
Other State-funded services. a/	33.4%
Volunteer services.	13.6%

a/ Other State-funded services include Case Management services not covered under the waiver, protection and advocacy services, and other long-term care services (e.g., physical, occupational, and speech therapies) covered under the regular State Medicaid Plan.

Source: La Jolla Waiver Survey (1985)

States reported that an average of 25 percent of their waiver clients were receiving vocational training services from other sources. Until recently, States were not permitted to include pre-vocational or vocational training services as part of their waiver benefit package, but the 1985 COBRA legislation specifically changed that policy and explicitly allows States to cover these services effective April 15, 1986 for waiver clients who enter the program directly from an institutional setting.

Waiver clients who are still in their school years are also likely to receive special education services funded through non-waiver services. A small minority were receiving special housing subsidies through the HUD Section 8 program, and/or receiving Medicaid home health services not funded under the waiver. A large percentage of waiver clients were receiving other services funded by the State or other sources not specifically listed in Exhibit 4-18.

DELIVERY SYSTEM ISSUES

Waiver Program Penetration Rates

A measure of the size of a State waiver program for the developmentally disabled is the ratio of waiver recipients to ICF-MR recipients plus waiver recipients. Exhibit 4-19 presents data on waiver program "penetration rates" which indicate the proportion of the total DD long-term care population served under the waiver. In other words, of the total number of developmentally disabled persons served by Medicaid who are "at-risk" of ICF-MR placement, what proportion are being served under the waiver? This measure assumes that all waiver recipients are at-risk of ICF-MR placement.

Waiver program penetration rates varied dramatically, from 2.7 percent in Wisconsin to 68.4 percent in Florida. In four States--Florida, New Hampshire, Alabama, and Nevada--the number of waiver recipients exceeded the size of the ICF-MR population. The overall penetration rate across all waiver programs combined was 23.0 percent. In other words, if one assumes that every waiver client is at-risk of institutional placement, then approximately one in four developmentally disabled persons at-risk of institutional care in the 29 States which provided these data is now being served under the waiver.

EXHIBIT 4-19

DD WAIVER PROGRAM PENETRATION RATES
N = 29

STATE	1985 UNDUPLICATED WAIVER RECIPIENTS	1985 UNDUPLICATED ICF-MR RECIPIENTS	PENETRATION RATE
AL	1,535	1,468	51.1%
CA	3,486	9,740	26.4%
CO	1,284	1,574	44.9%
DE	62	442	12.3%
FL	6,979	3,221	68.4%
HI	33	263	11.1%
IA	78	1,856	4.0%
ID	45	509	8.1%
IL	752	8,546	8.1%
KY	512	1,264	28.8%
LA	1,890	5,710	24.9%
MD	379	1,865	16.9%
ME	312	709	30.6%
MN	246	7,808	3.1%
MT	190	284	40.1%
NC	113	3,083	3.5%
ND	410	649	38.7%
NH	425	374	53.2%
NJ	2,046	4,027	33.7%
NM	53	624	7.8%
NV	363	205	63.9%
OR	415	1856	18.3%
PA	157	8,317	1.9%
PA	110	8,317	1.3%
RI	238	1,094	17.9%
SD	575	748	43.5%
VT	196	282	41.0%
WA	965	2,841	25.4%
WI	66	2,384	2.7%
WV	45	258	14.9%
Average:	799	2,677	
Overall Penetration Rate:			23.0%

Sources: La Jolla Waiver Survey (1985) and HCFA 2082 data.

This high level of program penetration in DD waivers differs markedly from penetration rates in waivers for the aged and physically disabled, as reported in Chapter Three. The overall penetration rate among waivers for the aged and physically disabled was 3.0 percent, and ranged from less than 1.0 percent to 15.5 percent in States which provided data on the survey. At these levels of program penetration, it is more reasonable to expect measurable impacts of DD waivers on aggregate ICF-MR utilization and costs at the State and national levels than to expect measurable impacts of waivers for the aged and physically disabled.

Reported Impacts of DD Waivers on the ICF-MR Delivery System

States reported that DD waiver programs were having substantial impacts on their ICF-MR delivery systems, as presented in Exhibit 4-20. The impacts reported most frequently were the continued depopulation of publicly-operated State facilities, the reduction of certified beds in these facilities, and, in some cases, the outright closing of facilities. Forty-four percent of responding States indicated that the waiver program had a direct impact on reducing the number of beds in public ICF-MRs. Four States reported that public ICF-MRs had been closed altogether as a result of the waiver. Ten States reported that the development of new beds in public ICF-MRs had been averted due to the waiver program, and 11 States reported reduced occupancy rates in their existing ICF-MR systems.

States reported less impact on privately-operated ICF-MRs. Only three States (11 percent) reported that the number of beds in privately-operated ICF-MRs had been reduced as a result of the waiver, and only 8 States (30 percent) reported that the development of new ICF-MR beds had been diverted. Four States reported that the Section 2176 waiver had been used to decertify existing small-scale ICF-MRs, converting these facilities to non-ICF-MR group homes and apartment programs financed through SSI/SSP funds, waiver funds, and other sources.

The majority of responding States reported an absolute decline in the number of ICF-MR beds between 1982 and 1985 (Exhibit 4-21). Of the 26 DD waiver States which provided data on the survey, 14 (54 percent) reported reductions in the number of occupied ICF-MR beds over this three-year period, while 12 (46 percent) reported increases. The largest absolute reduction occurred in California, which

EXHIBIT 4-20

Reported Impacts of Waiver Program on ICF-MR System

n = 27

	YES, but not due to Waiver	YES, due to Waiver	NO	No Response
ICF-MR beds in publicly-operated facilities have been reduced.	7	12	7	1
Publicly-operated ICF-MR facilities have been closed altogether.	1	4	22	0
New construction/conversion of public ICF-MR beds has been averted.	9	10	8	0
ICF-MR beds in privately-operated facilities have been reduced.	2	3	21	1
Waiting lists for ICF-MR placement have shortened.	4	7	13	3
New construction of private-operated ICF-MRs has been averted.	4	8	14	1
Conversion of privately-operated facilities to ICF-MR status has been diverted.	2	8	16	1
Small-scale ICF-MRs have been decertified under the waiver and converted to non-ICF-MR group home/apartment programs.	0	4	22	1
Occupancy rates in existing ICF-MR system have declined.	1	11	15	0
Occupancy rates in existing ICF-MR system have increased.	3	0	24	0

Source: La Jolla Waiver Survey (1985) Table indicates responses to the question: Since the waiver program was implemented, which of the following impacts on the ICF-MR program have occurred in your State and which of these are attributable to the waiver program?

EXHIBIT 4-21

CHANGES IN SUPPLY OF ICF-MR BEDS
IN WAIVER STATES
N = 26

STATE	TOTAL ICF-MR BEDS 6/30/82	TOTAL ICF-MR BEDS 9/30/85	CHANGE (85 MINUS 82)	PERCENT CHANGE
AL	1,470	1,430	-40	-2.7%
CA	10,374	7,967	-2407	-23.2%
CO	2,017	1,539	-478	-23.7%
DE	513	462	-51	-9.9%
FL	2,128	2,780	652	30.6%
HI	389	320	-69	-17.7%
IA	1,673	2,575	902	53.9%
ID	482	528	46	9.5%
KY	1,250	1,175	-75	-6.0%
MA	3,971	3,929	-42	-1.1%
MD	1,851	1,649	-202	-10.9%
ME	630	724	94	14.9%
MN	6,899	7,556	657	9.5%
MT	290	273	-17	-5.9%
NC	2,762	2,987	225	8.1%
NH	340	325	-15	-4.4%
NJ	4,366	3,861	-505	-11.6%
NM	553	590	37	6.7%
NV	175	187	12	6.9%
OK	1,803	2,966	1163	64.5%
PA	8,598	8,574	-24	-0.3%
RI	881	953	72	8.2%
SD	721	687	-34	-4.7%
VT	385	262	-123	-31.9%
WI	3,548	3,877	329	9.3%
WV	170	265	95	55.9%
Total:	58,239	58,441	202	0.3%

Sources: La Jolla Waiver Survey (1985) and the 1982 National Survey of Residential Care Facilities for the Mentally Retarded, University of Minnesota.

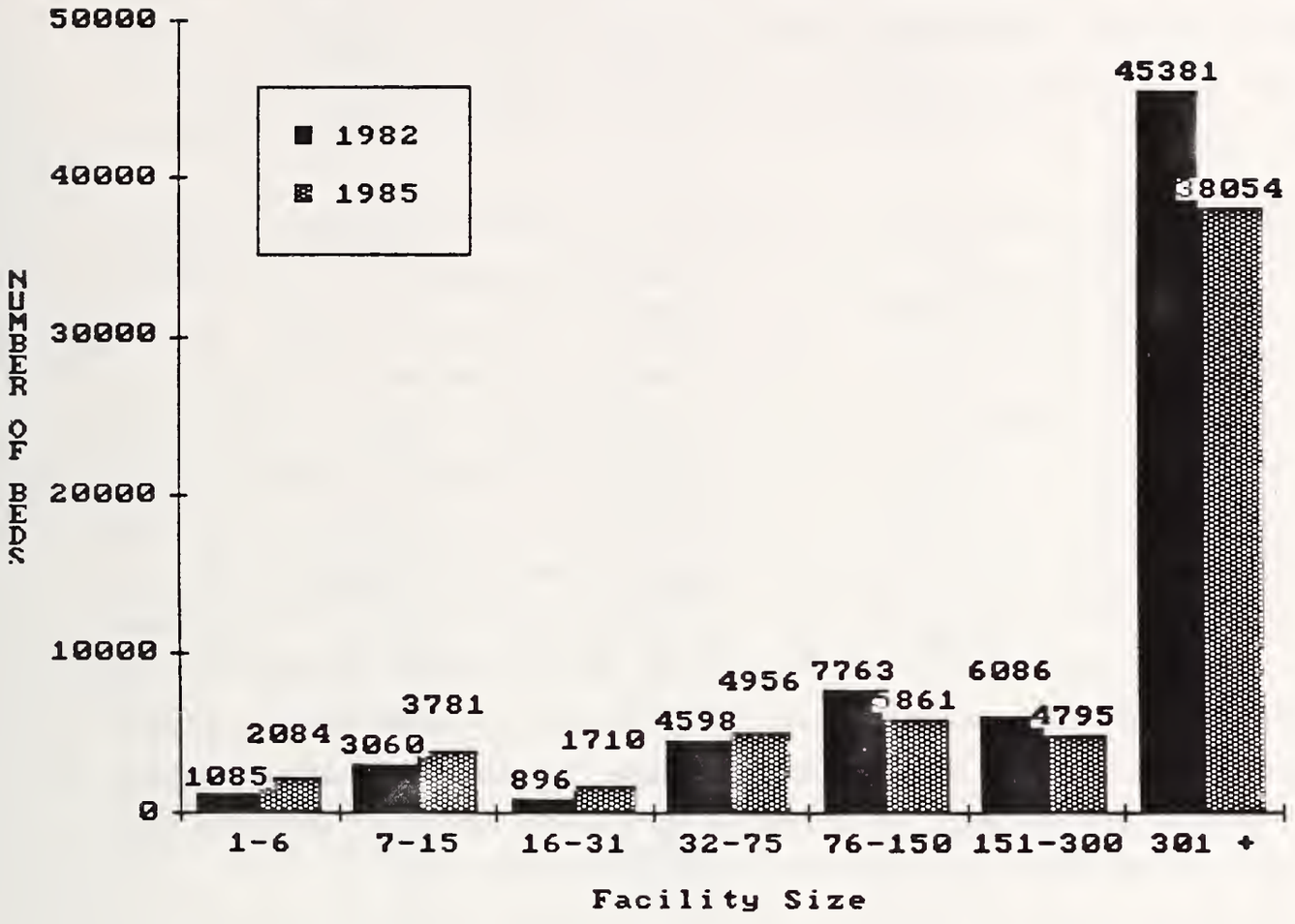
reported 2,407 fewer ICF-MR beds. The State with the greatest proportional reduction in ICF-MR beds was Vermont, which reported 32 percent fewer ICF-MR beds in 1985 than in 1982. California and Colorado both reported 24 percent declines over the three-year period.

Nine States indicated that a moratorium on new ICF-MR beds had been established since the implementation of their waiver programs and, of these, all but one reported that the availability of the waiver program was a contributing factor in the decision to establish such a moratorium. In two of these States (North Carolina and South Dakota), the moratorium has recently been lifted, presumably indicating the waiver program was not sufficient in scope to divert expansion in the supply of ICF-MR beds indefinitely.

In addition to changes in the overall supply of ICF-MR beds, the survey asked States to report changes in the distribution of ICF-MR beds according to the size of the facility in which they were located. These data are presented in Exhibit 4-22. The exhibit graphically portrays the shift in State ICF-MR systems from large-scale to small-scale ICF-MRs. Although most ICF-MR beds are still located in State-operated facilities with more than 300 beds, there was a 16 percent decline in the number of certified beds in these types of facilities, an absolute decline of 7,327 beds. There were also reductions in the number of beds in ICF-MRs with between 76 and 300 beds.

On the other hand, the number of beds in ICF-MRs with less than 75 beds have continued to increase. There was a 91 percent increase in the number of beds in facilities with 16-31 beds; a 24 percent increase in ICF-MRs with 7-15 beds; and a 92 percent increase in beds in ICF-MRs with less than 6 beds. Thus, it is apparent that the implementation of 2176 waiver programs is but one factor impacting State residential care systems for the developmentally disabled. An equally important development is the continued expansion of small-scale ICF-MRs, and the overall shift in the ICF-MR system from large-scale to small-scale facilities.

EXHIBIT 4-22
DIST. OF ICF-MR BEDS BY FACILITY SIZE



Source: La Jolla Waiver Survey (1985)

The Importance of the Waiver as a Funding Source for Community-Based Services

Expenditures for waiver services comprise a significant proportion of total expenditures for community-based services to the developmentally disabled in many States. States were asked to report the total State MR/DD budget for community-based services, excluding all ICF-MRs (regardless of whether they were community-based ICF-MRs) for their most recent fiscal year. In Exhibit 4-23, these budget figures are compared to reported FY 1985 expenditures for waiver services. Although the time frames usually differ somewhat, Exhibit 4-23 gives a rough estimate of the relative importance of the waiver program within each State's overall funding of community-based services for developmentally disabled persons.

The table shows that the waiver program is of greatest importance in smaller States, with relatively small budgets for community-based care. In Alabama, Colorado, Kentucky, Maryland, New Hampshire, Nevada, and South Dakota, expenditures for waiver services represented between 25 percent to 37 percent of total resources for community-based services. In Louisiana, prior to termination of its waiver program in December 1984, waiver resources represented almost all the resources not spent for ICF-MR care, although this is also due to the fact that almost all residential care in Louisiana is financed under the ICF-MR program. On the other hand, while larger States such as California, New Jersey, and Pennsylvania were spending considerable sums for waiver services, these expenditures still represented relatively small percentages of their total community-based services budgets. For example, the $25 million which the California Department of Developmental Services spent for waiver services in FY 1985 still represented only 7.4 percent of its $339 million budget for community-based services.

OVERSIGHT AND QUALITY ASSURANCE

Oversight of DD Waivers by State Medicaid Agencies

Section 2176 waiver programs for the developmentally disabled and chronically mentally ill have created new relationships between State Medicaid agencies, which have ultimate responsibility for waiver programs, and State MR/DD and State Mental Health agencies, which frequently have the day-to-day responsibility for their

Exhibit 4-23

DD WAIVER EXPENDITURES AS A PERCENTAGE OF TOTAL
STATE EXPENDITURES FOR COMMUNITY BASED SERVICES

STATE	FY 1985 WAIVER EXPENDITURES (DOLLARS)	TOTAL HCBC EXPENDITURES (DOLLARS)	WAIVER EXPEND. AS PERCENT OF TOTAL
AL	6,547,859	17,500,000	37.42 %
CA	25,160,256	339,168,000	7.42 %
CO	17,228,448	54,737,155	31.47 %
DE	429,673	7,100,000	6.05 %
HI	263,301	6,000,000	4.39 %
IL	9,686,846	121,100,000	8.00 %
KY	8,854,523	26,200,000	33.80 %
LA	10,728,930	11,200,727	95.79 %
MD	10,743,515	31,879,185	33.70 %
ME	1,395,260	18,000,000	7.75 %
MT	3,285,104	17,000,000	19.32 %
NC	621,102	36,439,867	1.70 %
NH	8,793,496	29,391,253	29.92 %
NJ	19,620,160	249,000,000	7.88 %
NM	393,279	10,246,219	3.84 %
NV	1,747,779	5,000,998	34.95 %
PA	2,536,271	244,263,000	1.04 %
RI	1,018,217	10,350,000	9.84 %
SD	4,510,496	17,020,752	26.50 %
WA	11,001,524	69,956,903	15.73 %
WI	741,682	4,700,000	15.78 %
WV	271,872	73,000,000	0.37 %
Total:	145,579,591	1,399,254,859	10.40 %

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1 a Jolla Waiver Survey (1985)

successful operation. Most State Medicaid agencies delegate significant administrative responsibility for the operation of 2176 DD/CMI waivers to State Mental Retardation and State Mental Health agencies.

Since State MR/DD and State Mental Health agencies often have limited experience with Medicaid program regulations and claims processing requirements, HCFA has encouraged State Medicaid agencies to retain close oversight of waiver programs which they do not directly administer. Exhibit 4-24 shows the extent of oversight which State Medicaid agencies have retained in DD/CMI waiver programs. In two-thirds of DD/CMI waivers, the State Mental Retardation/Mental Health agency conducts level of care assessments independently of the State Medicaid agency, but the Medicaid agency reviews level of care assessments in over half the waivers. State Medicaid agencies rarely get involved in reviewing individual care plans or the licensing of waiver providers, but are more likely to be involved in the development of reimbursement rates for waiver services, and in approving contracts with waiver service providers.

In many instances, waiver service providers serving DD/CMI waiver clients do not submit claims to the Medicaid agency directly. Rather, they continue their previous contractual arrangements with the State MR/MH agency, which reimburse providers directly, and then bill the State Medicaid agency later on. In many DD/CMI waiver programs, providers are small non-profit agencies which would have difficulty financing the payment lags which often occur in Medicaid claims processing.

The survey also asked which State agency was responsible for the State share of waiver service costs. In two-thirds of the States, the State MR/DD agency was responsible for paying the State share of waiver service costs; in the remaining one-third, the State share was the responsibility of the State Medicaid agency, other State agency, or costs were shared across agencies.

In most cases, the agency which paid the State share for waiver services was also responsible for the State share of ICF-MR costs. However, in 8 States, the MR/DD agency paid for waiver services while another agency paid for ICF-MR services, or costs were shared. This is of interest because the cost-effectiveness of

EXHIBIT 4-24

Oversight of DD/CMI Waivers by State Medicaid Agencies

n = 31

	Percent Responding Yes	No
a. State Medicaid agency conducts all level of care assessments independently of State MR Agency	35%	65%
b. State Medicaid agency reviews level of care assessments conducted by State MR Agency	52%	48%
c. State Medicaid agency reviews all individual care plans prior to implementation of waiver services	29%	71%
d. State Medicaid agency conducts own licensing/ certification of waiver service providers	16%	84%
e. State Medicaid agency approves reimbursement rates paid to providers for waiver services	53%	47%
f. State Medicaid agency approves contracts with waiver service providers	48%	52%
g. State Medicaid agency reviews claims made for waiver services to ensure compliance with established rates, cost caps, contracts, etc.	73%	27%
h. State MR agency pays waiver providers directly and then bills State Medicaid agency for waiver services	45%	55%
i. State Medicaid agency conducts its own audits of waiver service providers	35%	55%

Source: La Jolla Waiver Survey (1985)

a waiver program may be related to the degree of consolidation between ICF-MR budgets and waiver budgets. A State agency with no responsibility for ICF-MR costs may have less incentive to operate a cost-effective waiver program than a State agency which stands to reap the benefits of reduced ICF-MR expenditures from a well-targeted waiver program. However, there is no direct evidence that the cost-effectiveness of waiver programs is associated with the degree of consolidation in waiver and ICF-MR program budgets.

Financing of Case Management Services

Case managers have a central role in Section 2176 waiver programs, both in the initial assessment and screening of potential waiver recipients, and in monitoring the care provided to recipients once they are admitted to the program. Consequently, the survey elicited information concerning the structure and financing of case management-related activities in DD/CMI waiver programs.

Exhibit 4-25 shows wide variability across States in the financing of case management activities across programs. Similar activities could be funded as a case management waiver service in one State, a different waiver service in another State, a Medicaid administrative cost in another, and not funded by Medicaid at all in another. Some patterns are discernible, however. The initial screening and assessment of waiver program applicants, and decisions about whether applicants are admitted to the waiver were more likely to be financed as Medicaid administrative costs or through non-Medicaid funding, than as case management under the waiver. Case managers funded under the waiver tend not to become involved until the development of the initial care plan. Their primary responsibilities are in actually managing the care provided to waiver recipients--assisting clients in accessing non-waiver services, coordinating the delivery of services among multiple providers, and monitoring the quality of care provided. In this last task, quality of care monitoring by case managers was usually augmented by quality assurance activities conducted by other entities. It is apparent that most States take a multi-faceted approach towards ensuring that waiver recipients are receiving quality care.

The overall picture presented by Exhibit 4-25 is that the State Mental Retardation/Mental Health agency usually has the lead role in identifying waiver

EXHIBIT 4-25

How Case Management-Related Activites Are Financed in DD/CMI Waivers

n = 36

Case Management-Related Activities	Activity is Funded as.... Case Management Waiver Service	Other Waiver Service	Medicaid Admin. Cost	Non-Medicaid Funding	Multiple Funding Sources	No Response
a. Initial assessment/screening of waiver program applicants	10	1	7	14	4	0
b. Level of care determinations	3	2	16	6	9	0
c. Determination of costs of community care for waiver applicants	6	1	12	13	3	1
d. Final determination of clients' acceptance into the waiver program	3	2	20	7	4	0
e. Initial care plan development	17	7	1	5	6	0
f. Assisting clients in obtaining non-waiver services	24	1	2	8	1	0
g. Coordinating delivery of waiver services	26	1	2	3	3	1
h. Monitoring quality of care provided	4	0	9	7	16	0
i. Review/approval of claims for waiver services (i.e., whether they correspond to services approved in case plan)	2	1	18	7	7	1
j. Periodic level of care redetermination	8	3	19	2	4	0
k. Determination of client cost-sharing liability	5	0	19	8	1	3

Source: La Jolla Waiver Survey (1985)

program candidates and in conducting level of care reviews. After the screening and assessment process is completed, the lead agency is likely to hand over case management responsibilities to a different entity, which is funded directly under the waiver. In quality assurance activities, however, multiple agencies are likely to be involved.

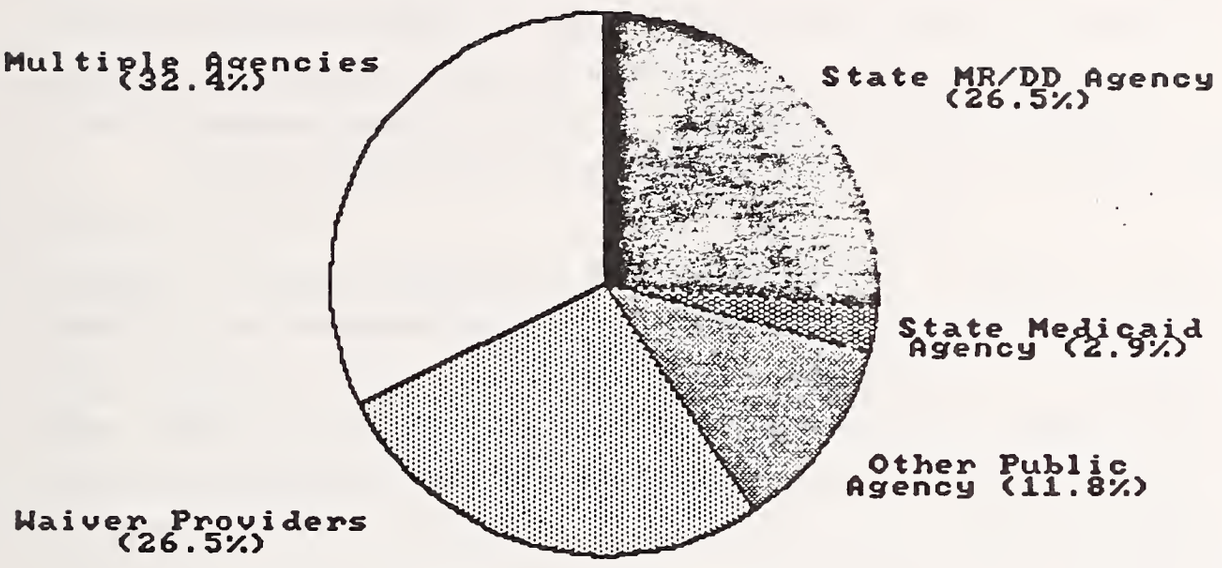
For those case management activities which were funded directly as a waiver service, the survey asked who case managers worked for (Exhibit 4-26). Again, there was considerable variation across States. In nine (27 percent) waiver programs, case managers worked directly for the State MR/DD agency. In nine other programs, case managers worked for waiver service providers. In 11 programs, case managers funded under the waiver worked for multiple types of agencies. In several programs, case managers worked for local/county mental retardation or social services agencies. Only in Iowa's waiver program, no longer in operation, were case managers located solely in the State Medicaid agency.

Standards and Procedures Employed to Ensure Quality of Waiver Services

The objective of the Section 2176 waiver program is not only to provide home and community-based care at an equal or lower cost to ICF-MR care, but to provide care that is at least equal, if not superior, in quality to ICF-MR care. The waiver formula itself focuses exclusively on the cost of what Medicaid programs are buying on both sides of the equation, not what they are buying. In evaluating Section 2176 waivers for the developmentally disabled, it is important to keep in mind that the cost impacts of the program, positive or negative, must be qualified by information on the quality of services being provided, in order to arrive at a true assessment of a waiver's success or failure.

Quality of care is difficult to measure without actual data on client outcomes. Nevertheless, the survey asked States to describe the procedures which they have established to monitor the quality of care provided to developmentally disabled waiver clients and to discuss any quality assurance problems which have arisen during waiver program implementation.

EXHIBIT 4-26
WHO CASE MANAGERS WORK FOR
N = 34 PROGRAMS



Source: La Jolla Waiver Survey(1985)

In most DD waivers, licensing and certification requirements for providers were not specifically developed for the waiver, but were adopted from pre-existing community-based service systems. In other words, all waiver States had developed community-based delivery systems for the developmentally disabled to some extent prior to their waiver programs, and had utilized the same quality assurance mechanisms in their waivers. Four States, however, reported that they had developed more stringent requirements for their waiver program providers than for their generic community-based service providers.

In 25 of 32 DD/CMI waiver programs (75 percent), the individual care plan was prepared by an interdisciplinary team which generally included one or more representatives from the waiver provider. The waiver provider usually participated in the preparation of the care plan, but did not have final authority over its content. In only three programs was the care plan developed by a case manager employed by the waiver service provider. In the remaining four programs, the care plan was developed by a case manager not associated with the provider agency.

As shown in Exhibit 4-27, most States have developed multi-level quality assurance mechanisms to monitor the care provided to waiver clients. In two-thirds of the programs, an independent review of the care plan was conducted. In virtually all programs, providers were monitored to ensure that care plans were properly implemented, and this monitoring included the direct observation of clients by an independent quality assurance monitor. In 27 of 31 reporting programs, monitors compared actual client outcomes with the treatment objectives specified in the care plan to determine the degree of client progress toward individualized goals.

In describing quality of care issues which have arisen in their waiver programs, States reported a variety of specific problems, but many fell into two broad areas: (1) problems implementing case management systems; and (2) problems in training providers to serve more severely disabled clients.

One objective of the Section 2176 waiver program is to stimulate more highly developed case management systems. Several States reported that they had encountered problems implementing case management systems which conformed to waiver program requirements. Several States reported that they simply did not have

EXHIBIT 4-27

State Approaches to Quality Assurance in DD/CMI Waivers

n = 31

	Yes		No	
	n	%	n	%
The plan of care is reviewed by someone not involved in its preparation prior to the implementation of waiver services.	21	68%	10	22%
Providers are monitored to ensure that plans of care are implemented properly.	30	97%	1	3%
Monitoring of provides includes the direct observation of clients.	29	94%	2	6%
Program monitoring includes the comparison of care plan objectives with actual client outcomes.	27	87%	4	13%

Source: La Jolla Waiver Survey (1985)

enough case managers in place to fulfill program requirements, and were attempting to build their case management staff. Other States, in which local case managers had traditionally exercised considerable autonomy in their work, reported problems in getting case managers to conform with the more uniform standards and procedures developed in their waiver programs, particularly in keeping the file documentation required by HCFA regulations for individual care plans, level of care assessments, consumer choice of waiver services, and client recertifications. Several States said that they were continuing to work with case managers and providers to develop more individualized training programs for waiver clients.

Problems with waiver providers were more likely to be reported by States which were serving severely disabled clients. One State reported that waiver providers lacked experience in dealing with "behaviorally challenging" clients and another reported difficulties in recruiting and keeping residential program staff who could work with their waiver program population. Clearly, if the Section 2176 waiver is increasingly used to depopulate State institutions, then States must concurrently place major emphasis on the development and training of community-based providers who are capable of serving this population.

Among other quality assurance problems cited by States were the difficulty in providing waiver clients with access to mainstream medical services and therapies (a problem endemic to the developmentally disabled population as a whole); lack of a computerized data system to track waiver clients and providers; and problems in getting non-waiver providers to accept waiver clients into their programs since they felt that the responsibility for waiver clients fell solely to those providers which were being financed under the waiver.

CHAPTER FIVE
STATE PERSPECTIVES ON ADMINISTRATION OF THE WAIVER PROGRAMS

The survey asked States to respond to two open-ended questions designed to get their opinion of how well their programs were operating, and how well the Section 2176 waiver authority was being interpreted and administered by the Health Care Financing Administration. The questions were:

> "What has been the most problematic aspect of waiver program implementation and operation?"
>
> "How might the HCFA waiver formula, regulations and program administration be improved to permit your State to meet its waiver program objectives?"

STATE OPERATIONAL PROBLEMS

The most frequently reported operational problem for the A/D waivers was the cost-sharing requirement which fell on some recipients. States felt that their clients were generally unwilling or unable to help pay for the cost of providing waiver services. Specifically, they advocated the elimination of the cost-sharing requirement that waiver applicants can keep an amount no greater than the SSI income level. They advocated that this income limitation was originally designed for persons about to live in a nursing home and is inappropriate for individuals who would remain in their homes.

Another problem expressed by several A/D administrators was the difficulty of coordinating administrative roles when authority for the waiver is split between two or more public agencies. These officials expressed concern that overlapping responsibilities can create problems with data collection, oversight, reporting, and the reconciliation of competing agency goals. A third area was the apparent difficulty in gathering county level data for making statewide projections. Only a few States reported difficulty in finding home and community care services providers.

In contrast, several State DD/CMI waiver program managers reported their chief problem was a shortage of qualified and interested service providers. This slowed down expansion of the program.

REGULATORY PROBLEMS

Over half of the States with either A/D or DD/CMI waivers stated that HCFA regulatory and reporting requirements posed significant obstacles to the success of their program. Complaints ranged from what was felt to be inordinate delays in obtaining approval of waiver amendments ("a minimum of six months") to the need to require simple and unambiguous statistical reports. HCFA was cited time and time again for excessive program and fiscal documentation, given the small size of the dollars involved. Further, States suggested a need to revise the waiver formula, eliminate the cap on program growth, and the desirability of making home and community care services optional under Medicaid State plans.

One-third of the States suggested that the waiver formula be revised. The most frequent assertion was that HCFA stop penalizing States which have worked successfully to contain excess nursing home bed growth. The existing regulation calls for evidence of the need for additional bed capacity in the absence of the waiver. States argue that this so-called "cold bed" policy be dropped. Another suggestion was that HCFA formula and reporting forms use "patient-years" instead of "unduplicated recipients" in the interest of obtaining the most accurate data on the average and projected cost of waiver services. Use of a FTE-type calculation would eliminate needless arguments about whether a new recipient could be substituted for a terminated one.

APPENDIX A

OMB Number 0938-0349
Approved through 12/31/86

Survey of Section 2176 Home and Community-Based Medicaid Waiver Programs

Survey of Waiver Programs for the Aged and Physically Disabled

Second Annual Survey

January 1986

Please Return to: La Jolla Management Corporation
11426 Rockville Pike, Suite 400
Rockville, Maryland 20852

Attention: Robert Clinkscale
Project Director
(301) 468-0100

This survey is being conducted under HCFA contract number 500-83-0056 with the Office of Research, Health Care Financing Administration, Department of Health and Human Services.

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OMB Number 0938-0349
Approved Through 12/31/86

SECOND ANNUAL SURVEY: OCTOBER 1, 1984 - SEPTEMBER 30, 1985
SECTION 2176 HOME AND COMMUNITY-BASED
MEDICAID WAIVER PROGRAMS

SURVEY FOR IMPAIRED ELDERLY AND OTHER
PHYSICALLY DISABLED

STATE _____ HCFA WAIVER ID# _____

This is the second annual survey of the Section 2176 Home and Community Based Medicaid Waiver Programs. This survey is designed to build upon the information gained through last year's survey and provide additional information on the specific operations of the waiver programs. We appreciate your time and cooperation.

I. WAIVER ADMINISTRATION

What State agency has lead responsibility for the day-to-day operations of the Medicaid Waiver program? Circle one response only.

State Agency on Aging. 1
State Human Services Agency. 2
State Medicaid Agency. 3
Other State agency (specify)_____ . 4
Other Public agency (specify)_____ . 5
Other Private agency (specify)_____ . 6

Lead Agency		State Medicaid Agency	
Agency Name	_____	Agency Name	_____
Address	_____	Address	_____
	_____		_____
	_____		_____
	_____		_____
Phone	(___) _____	Phone	(___) _____

PRIMARY CONTACT PERSON (Person to call with questions about responses to this survey.)

Name: _____
Title: _____
Address: _____
_____
_____

Telephone: (___)_____

HCFA Form #431

II. PROGRAM OVERVIEW

1. What was the effective date of the original waiver?
(If effective date was revised, indicate revised date.)

Effective Date . . . . . ____/____/____
MO DY YR

2. Has your program been implemented (i.e., have clients received services under the waiver?)

Yes 1
No 2

IF YES, on what date did the program first began serving clients?

Implementation Date . . . . . ____/____/____
MO DY YR

3. TARGET POPULATIONS REPORTED ON THIS SURVEY

Originally waivers were allowed to serve multiple target groups under the same waiver. For research purposes, however, we ask that a separate survey be completed for waivers serving the Aged/Disabled and for waivers serving the Developmentally Disabled and/or Chronically Mentally Ill. This survey is designed for programs serving the aged/disabled groups. Please indicate which specific aged/disabled target populations are served under this waiver program and reported on this survey.

a. Aged 65 + ... 1

b. Physically disabled under 65. 1

c. Other (Specify)_____ . . . 1

4. SERVICES APPROVED UNDER THE WAIVER

Below is a list comprising the most common types of waiver services offered under existing waivers. We realize that the 2176 legislation purposely allowed States flexibility in what services to offer and how to define those services. For research purposes, however, we need to obtain information within a common set of service categories in order to make comparisons across programs.

DIRECTIONS: Please indicate which services below are approved under your waiver to the target group specified in the previous question. Based on data from last year's survey, we have grouped some of the less common services into broader categories. If the exact name of your service is not listed, please try to place it in one of the predetermined categories if possible.

Circle each service approved under the waiver.

a. Case Management 01

b. Screening and Assessment (if reimbursed separately from Case Management) 02

c. Personal Care (circle all that apply) 03
- Cleaning 1
- Shopping/errands 1
- Meal planning. 1
- Bathing. 1
- Grooming 1
- Dressing 1
- Medication Monitoring. 1
- Toileting. 1
- Transferring 1
- Ambulation 1
- Eating/Feeding 1
- Yard Work. 1
- Minor Home Repair. 1
- Financial Management 1
- Companion Services 1
- Teaching 1

d. Homemaker (circle all that apply) 04
- Cleaning 1
- Shopping/errands 1
- Meal planning. 1
- Bathing. 1
- Grooming 1
- Dressing 1
- Medication Monitoring. 1
- Toileting. 1

(Continued on next page)

d. Homemaker (Continued)
- Transferring 1
- Ambulation 1
- Eating/Feeding 1
- Yard Work. 1
- Minor Home Repair. 1
- Financial Management 1
- Companion Services 1
- Teaching 1

e. Respite (circle all that apply). 05
- In-home respite--hourly 1
- In-home respite--overnight 1
- Out-of-Home overnight respite--non-medical (e.g., congregate living) 1
- Out-of-Home overnight respite--residential (e.g., Board & Care homes) 1
- Out-of-Home overnight respite--nursing home 1
- Out-of-Home respite--hourly 1

f. Home Health Aide (includes services such as medical attendant care, etc) 06

g. Adult Day Health (includes other services that include some of the activities listed below, e.g., Social/Day Care, Adult Day Care, etc. 07
(Circle all that apply)
- Social/recreational activities 1
- RN monitoring/supervision 1
- MD monitoring/supervision 1
- Low Tech Physical Therapy 1
- High Tech Physical Therapy 1
- Other therapy (OT, speech) 1
- Transportation 1

h. Habilitation Services 08

i. Other Services (circle all that apply) 09

Sheltered living arrangement (includes residential and foster care services such as Residential Supervision, Congregate Care Services, Satellite Apartment Programs, Adult Foster Care, and Adult Family Home 1

(Other Services, Continued from Previous page)

Skill development and Instructional ADLs (includes patient development services such as nutritional counseling, psychiatric services, developmental training, and daily living skills 1

Personal Support (includes support services such as night support, companion escort, protective services). 1

Medical supplies and equipment (includes minor assistive devices). 1

Emergency Response. 1

Meals 1

Skilled Nursing 1

Transportation. 1

Therapies 1

Housing Modifications 1

Other (Specify) _____ . . 1

5. Please indicate how the following Assessment/Case Management/Quality Assurance activities are supported and whether they are performed by case managers or others. In the reimbursement columns, indicate whether the activities are reimbursed as a service under the definition of case management services, as part of a different waiver service, or whether the activity is supported through non-waiver funding, either State Medicaid administrative funds or other non-Medicaid funds. (Note: if the State reports a cost on the HCFA-64 as a Medicaid administrative cost and does not include the cost on the HCFA-372, then indicate that the service is a State Medicaid administrative cost.)

	Activity is Reimbursed as				Case Mgr. Performs
	Case Management Waiver Service	Other Waiver Service	Medicaid Admin. Cost	Non-Medicaid Funding	
a. Comprehensive initial assessment/ screening of waiver program applicants	1	2	3	4	1
b. Level of care determinations	1	2	3	4	1
c. Determination of costs of community care for waiver applicants	1	2	3	4	1
d. Final determination of clients' acceptance into the waiver program	1	2	3	4	1
e. Initial care plan development	1	2	3	4	1
f. Assisting clients in obtaining non-Medicaid/non-waiver community based services, e.g., Meals-on-Wheels	1	2	3	4	1
g. Coordination of delivery of waiver services	1	2	3	4	1
h. Monitoring quality of care provided	1	2	3	4	1
i. Review/approval of claims for waiver services (i.e., whether they correspond to services approved in care plan)	1	2	3	4	1
j. Assessing client's progress and continued appropriateness in the waiver program	1	2	3	4	1
k. Periodic level of care redetermination	1	2	3	4	1
l. Determination of client cost-sharing liability and/or maintenance of client cost-share contribution records	1	2	3	4	1

6. Persons who conduct the activities listed in Question 5 which are <u>reimbursed under the waiver</u> are employees of what types of agencies? Persons who are case managers are employees of what types of agencies?

Circle all that apply.	Agency Reimbursed for Services	Agency Employing Case Managers
a. State or local Health Dept	1	2
b. State Agency on Aging	1	2
c. State or local Social Services/Human Resources	1	2
d. State or local Medicaid/Public Welfare	1	2
e. Other State agency (specify)	1	2
f. Other public agency (specify)	1	2
g. Local Agency on Aging	1	2

7. What is the average monthly workload for a case manager?

a. Average monthy active caseload per FTE case manager |__|__|__|__|

b. Average monthly waiver clients with direct case manager contact per FTE case manager |__|__|__|__|

c. Average number of comprehensive assessments per month per FTE case manager (if applicable), <u>not</u> including those for active clients |__|__|__|__| N/A

If teams are used, estimate cases per case manager by dividing the total caseload by the number of full-time equivalent (FTE) individuals performing case management. If case managers also perform non-waiver functions or waiver functions other than case management/assessment related tasks, use FTEs devoted to case management/assessment tasks to calculate case load per case manager. The active caseload includes all active clients whether or not they received case management services in the month.

III. OTHER WAIVER PROVISIONS

8. Do you presently have a waiver of statewideness? Circle one response only.

   a. Yes, but services are nonetheless available statewide. . . . 1

   b. Yes, waiver services are restricted to specific geographic areas 2

   c. No 3

9. In how many counties are waiver services available?

COUNTIES W/ OPERATIONAL WAIVER PROGRAM	TOTAL COUNTIES IN STATE
|___|___|___|	|___|___|___|

10. Does the State plan to eventually make services available statewide?

Yes 1
No 2
Uncertain 3
Program already Statewide 4

11. Does your State Medicaid program currently have a Medically Needy program?

Yes 1
No 2

IF YES, has eligibility for the waiver program been extended to Medically Needy applicants?

Yes 1
No 2

IF NO, has your waiver program exercised the option to extend eligibility to persons who qualify under a Special Income Level (the "300% rule")?

Yes 1
No 2

12. Has your waiver program exercised the option to apply the institutional deeming rules in determining eligibility for waiver program applicants?

Yes 1
No 2

13. If you use institutional deeming rules and/or expand eligibility under the 300% rule, please estimate the percentage of clients admitted in the past year under these waiver provisions.

_____%

14. Has your waiver program exercised the option to deny waiver services to persons for whom the cost of home and community-based care is estimated to exceed the cost of nursing home care or other cost cap?

Yes 1
No 2

IF YES, what is the specified cost limit in dollars per month and as a percentage of the average monthly Medicaid nursing home reimbursement?

$ |__|__|__|__|.0|0| per month

|__|__|__| % of average monthly Medicaid reimbursement.

IF YES, what cost elements are considered under the cost-cap? Circle one response only.

Waiver service costs vs. average monthly Medicaid nursing home payment. 1

Total Medicaid costs for the waiver client vs. average total Medicaid costs for nursing home residents. 2

Total costs of care in the community including Medicaid and other public costs vs. the total costs for nursing home residents. 3

IV. SCREENING/ASSESSMENT/INTAKE

15. Eligibility for the waiver program is restricted to:

(Circle all that apply)

a. Persons located in specific types of institutions or care settings at the time of screening

Acute Care Hospital. 1

SNF 2

ICF 3

Other _____ 4

b. Persons who have applied for nursing home Medicaid coverage and/or nursing home placement 1

c. Eligibility is not restricted other than for categorically ineligible (see question 3). 1

d. Other (Specify)_____ 1

For the questions that follow--Pre-Admission Screening (PAS) is defined as a comprehensive, mandatory assessment of nursing home applicants who are Medicaid eligible or would become eligible within one month of the assessment. It may also include those individuals who would "spend-down" to Medicaid eligibility within a period of time specified by the State. ("Spend-downs" are defined as individuals who are not immediately eligible for Medicaid but would deplete their own resources to become Medicaid eligible within a period of time after entering an institution.)

16. Does your State have a pre-admission screening program?

Yes 1
No 2

IF NO, skip to Item # 22.

IF YES, is the PAS program operational in all counties served by the waiver?

Yes 1
No 2

17. Is the PAS program restricted to nursing home applicants in certain settings (e.g., in an acute care hospital)?

Yes 1
No 2

18. Does the PAS program cover potential "spend-downs"?

Yes 1
No 2

IF YES, PAS is required for persons who will "spend down" within how many months? . . . . . |__|__|

19. Is the assessment process for the waiver program part of the PAS program?

a. Yes, the waiver assessment process is included in a formal PAS program 1

b. Yes, all nursing home applicants that have been approved for nursing home level of care in pre-screening are required to be referred to the waiver program for assessment 2

c. Yes, Only those pre-screened nursing home applicants that are potentially appropriate for community care are referred to the waiver program for further assessment 3

d. No, but some referrals are made to the program from the PAS program. 4

e. No, there are no referrals from any PAS program 5

If you answer d or e, skip to 22.

20. Have you experienced any problems with potential waiver clients not being referred from PAS? (e.g., are potential waiver clients being lost because they are not referred?)

Yes 1
No 2

21. If waiver program assessment is directly linked with PAS (answers a, b, or c to question 19), must all waiver program applicants go through PAS? (i.e., can persons be admitted to waiver program without going through PAS?)

Yes 1
No 2

22. What formal criteria, if any, does your program use in addition to Level of Care criteria to deny admission to the waiver program?

a. There are no restrictions 1

b. Certain diagnostic situations 1
(e.g., alcoholism, mental illness)

c. Certain social situations 1
(e.g., housing inappropriate given mobility limitations, lack of personal physician, etc.)

d. No family or informal support 1

e. Adequate family or informal support 1

f. Other _____ 1

g. Other _____ 1

V. ENROLLMENT AND DISENROLLMENT

23. What is the total number of persons ever enrolled in your waiver program as of September 30, 1985? (Waivers that have been renewed, or that have been designated as new waivers but that still serve the original client population should count all persons admitted in the original three year waiver, plus those admitted in the extended waiver.)

Total persons ever enrolled |__|__|__|__|__|__|

Actual data - 1 Estimated - 2

24. Of those who were admitted to the program during the year 10/1/84 to 9/30/85, how many clients were admitted from each of the following entry points? (Point of entry is defined as the client's institutional or residential location at the time of initial assessment of determination of program eligibility). IF ACTUAL DATA ARE NOT AVAILABLE, PLEASE PROVIDE ESTIMATES.

Entry Point	Number of Waiver Admissions
Long-term Care Institutions (e.g., SNFs or ICFs)	|__|__|__|__|__|
Group Residence	|__|__|__|__|__|
Private Residence:	|__|__|__|__|__|
Living Alone	|__|__|__|__|__|
Living with Parents or Adult Children	|__|__|__|__|__|
Living with Spouse	|__|__|__|__|__|
Shared Living Arrangements with Other Relatives	|__|__|__|__|__|
Shared Living Arrangements with Non-Relatives	|__|__|__|__|__|

Acute Care Hospital:
(For those coming from the hospital, please indicate the entry point prior to hospital admission.)

Long-Term Care Institution	|__|__|__|__|__|
Group Residence	|__|__|__|__|__|
Private Residence	|__|__|__|__|__|
Don't Know	|__|__|__|__|__|

The Above Responses Are:

Estimated Data - 1 Actual Data - 2

25. Please indicate the number of unduplicated recipients served by the waiver program in each waiver year. Admission date for each individual is defined as the first date of service.

Waiver Year	Annual Unduplicated recipients
Year 1	|__|__|__|__|__|
Year 2	|__|__|__|__|__|
Year 3	|__|__|__|__|__|
Year 4	|__|__|__|__|__|

26. What was the current active caseload of your waiver program on September 30, 1985?

Caseload on 9/30/85 . . . . . \|__\|__\|__\|__\|__\|

Actual data - 1 Estimated - 2

27. For each year of the waiver, has the actual recipient count based on the number of UNDUPLICATED recipients differed by more than 10% from your original waiver application projections or approved modified projections of waiver recipients? Circle one response for each year.

	Year 1	Year 2	Year 3	Year 4
Recipients served exceeded projections	1	1	1	1
Recipients served fell below projections	2	2	2	2
Recipients served were as projected	3	3	3	3

28. How many waiver applicants have undergone the waiver assessment process from October 1, 1984 to September 30, 1985 (include only those individuals who have been pre-screened and further considered for the waiver program)?

Persons assessed 10/1/84-9/30/85 \|__\|__\|__\|__\|__\|__\|

29. How many of those assessed were subsequently admitted to the waiver program?

Persons Admitted 10/1/84-9/30/85 |__|__|__|__|__|__|

30. How many of those assessed were subsequently not admitted to the waiver program?

Persons Not Admitted 10/1/84-9/30/85 |__|__|__|__|__|__|

31. What percentage of waiver applicants assessed from 10/1/84 to 9/30/85 were NOT ADMITTED to the waiver program for each of the following reasons?

	Percentage
a. Client ineligible:	
did not meet level of care criteria	____%
did not meet Medicaid eligibility criteria	____%
did not meet waiver program restrictions (See question 15)	____%
b. Client inappropriate for community services:	
institutional care was recommended	____%
cost of community care too expensive	____%
services needed by client not available through waiver program	____%
diagnostic situations (e.g., alcoholism, mental illness)	____%
social situations (e.g., housing inadequate, lack of personal physician, etc.)	____%
no family or informal support	____%
adequate family or informal support	____%
other _____	____%
c. Client refused waivered services:	
client chose to remain in community without waivered services	____%
client chose institutional care	____%
d. Client died before being admitted to the waiver program	____%
e. Waiver program had reached caseload limit and was unable to accept client (client may have been put on a waiting list)	____%
f. Other _____	____%

The Above Responses Are: Estimated Data - 1 Actual Data - 2

32. As of September 30, 1985, how many persons ever admitted to the waiver program were enrolled for each of the following time periods? Please report length of stay from admission separately for persons who have been discharged and persons who are still active clients.

Enrolled for:	Number of Persons: Discharged as of 9/30/85	Still enrolled as of 9/30/85
Less than one month.	|__|__|__|__|__|	|__|__|__|__|__|
One month to less than three months .	|__|__|__|__|__|	|__|__|__|__|__|
Three months to less than six months .	|__|__|__|__|__|	|__|__|__|__|__|
Six months to less than nine months .	|__|__|__|__|__|	|__|__|__|__|__|
Nine months to less than one year . .	|__|__|__|__|__|	|__|__|__|__|__|
One year to less than 18 months . . .	|__|__|__|__|__|	|__|__|__|__|__|
18 months to less than 2 years	|__|__|__|__|__|	|__|__|__|__|__|
2 to less than 3 years	|__|__|__|__|__|	|__|__|__|__|__|
3 years or more.	|__|__|__|__|__|	|__|__|__|__|__|

Above responses are: Actual data - 1 Estimated - 2

33. Of persons who were disenrolled from the waiver program between October 1, 1984 and September 30, 1985, what is the primary reason each individual was discharged? If actual data are not available, please provide estimates.

Death	|__|__|__|__|__|
Nursing home placement (actual or anticipated). . .	|__|__|__|__|__|
Did not meet level of care criteria at reassessment	|__|__|__|__|__|
Lost Medicaid eligibility	|__|__|__|__|__|
Moved out of service area	|__|__|__|__|__|
Community care costs exceeded cost cap.	|__|__|__|__|__|
Program lost track of client.	|__|__|__|__|__|
Client voluntarily disenrolled (but stayed in community)	|__|__|__|__|__|
Other (specify) _____	|__|__|__|__|__|
Don't Know.	|__|__|__|__|__|

The Above Responses Are:

Actual Data - 1 Estimated - 2

VI. SERVICE UTILIZATION AND EXPENDITURES

34. Please complete the table below for each waivered service delivered during the period 10/1/84 - 9/30/85.

	UTILIZATION AND EXPENDITURE CHARACTERISTICS			
Waiver Services (1)	Total Expenditures (2)	Unduplicated Recipients (3)	Average Cost Per Unit of Service(4)	Provider Reimburse-ment Method (5)

NOTE: Column (1). List each waivered service provided.
Column (2). Total expenditures by type of service.
Column (3). Estimate unduplicated recipients.
Column (4). Estimate average cost per unit of service and identify units; e.g., $22.00/hr.for homemaker visit, $50.00/ month of case management service, etc.
Column (5). Code "1" for fee-for-service,
Code "2" for capitation arangement, or
Code "3" for other (specify other)

35. Please provide the following overall program statistics for the 10/1/84 - 9/30/85 time period. (Note: "Total days of waivered coverage" refers to the sum of enrollment days for all persons covered by the waiver.)

a) Total unduplicated recipients _____

b) Total days of waivered coverage _____

36. Have the reimbursement rates established for the waiver program been an impediment to attracting an adequate supply of providers for waiver services?

Yes 1
No 2

Please explain any problems encountered. _____

_____

_____

37. When actual average per capita waiver service costs for waiver clients are compared to projected average per capita costs in each waiver year:

	YEAR 1	YEAR 2	YEAR 3
a. Average per capita costs exceeded projected costs by more than 10% . . .	1	1	1
b. Average per capita costs were less than projected costs by more than 10% .	2	2	2
c. Average per capita costs were within 10% of projected per capita costs . .	3	3	3

If average per capita costs were <u>higher or lower</u> than projected, explain the reasons for the variances below.

_____

_____

_____

VII. INFORMAL CARE

38. Are there specific program guidelines or requirements used in intake assessment and/or care planning that take into account the availability of informal care provided by family and friends?

Yes 1
No 2

IF NO, skip to 40.

39. What are the guidelines? Circle all that apply.

a. Clients must have an informal caregiver in order to be admitted to the waiver program 1

b. Informal caregivers must be able or agree to contribute a specified amount of time each week (may vary with clients needs). 1

c. Waiver services are generally not authorized/provided to meet care needs already being met by informal caregivers (except for respite purposes) 1

d. Waiver services may be authorized/provided to meet needs already being met by informal caregivers but only where the informal caregivers agree to redirect their efforts to other needs not being met 1

e. Other _____ 1

40. Of those clients who were ever admitted to the program from a non-institutional setting (i.e., either a group or private residence) what percent were receiving long-term care services from formal and/or informal sources prior to enrollment? FORMAL SOURCES ARE PAID PROVIDERS, INFORMAL SOURCES ARE FAMILY AND FRIENDS.

	Percent of Clients
Formal sources only.	|__|__|__|
Informal sources only.	|__|__|__|
Both formal and informal sources	|__|__|__|
Not receiving services from any source	|__|__|__|
Don't Know	|__|__|__|

The Above Responses Are: Estimated Data - 1 Actual Data - 2

VIII. CHARACTERISTICS OF WAIVER PROGRAM POPULATION

For waiver recipients who were enrolled in the program as of September 30, 1985, please provide data on the following characteristics:

41. Age by sex: NUMBER OF ENROLLEES

	Male	Female	Total
0-21	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
22-34	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
35-44	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
45-54	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
55-64	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
65-74	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
75-84	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
85+	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|
TOTAL	|__|__|__|__|__|	|__|__|__|__|__|	|__|__|__|__|__|

42. Marital Status: Number of enrollees in each category as of September 30, 1985.

	Number of Enrollees
Married.	|__|__|__|__|__|
Never Married.	|__|__|__|__|__|
Divorced/Widowed/Separated	|__|__|__|__|__|

The Above Responses Are:
Estimated Data - 1 Actual Data - 2

43. Activities of Daily Living (ADLs)

Please indicate the number of new admissions from 10/1/84 thru 9/30/85 in each category.

THIS SHOULD BE AN UNDUPLICATED COUNT OF ADMISSIONS. PLACE ENROLLEES IN MOST SEVERE DEPENDENCY CATEGORY WHICH APPLIES. NO ENROLLEE SHOULD BE COUNTED IN MORE THAN ONE CATEGORY IN THE FOLLOWING CONTINUUM.

ADL Level	Number of Enrollees
4 - Human help needed in toilet and/or eating (most severe dependency level)	|__|__|__|__|__|__|
3 - Human help needed in bathing and/or dressing.	|__|__|__|__|__|__|
2 - Human help needed in mobility only.....	|__|__|__|__|__|__|
1 - No human help needed in Activities of Daily Living (least severe dependency level).....	|__|__|__|__|__|__|
Total (should be equivalent to #29)	|__|__|__|__|__|__|

The Above Responses Are:
Estimated Data - 1 Actual Data - 2

DEFINITIONS OF ADL DEPENDENCIES:

Toileting: Person has difficulty controling bowels, bladder or both; or has had an ostomy (i.e., a surgical procedure which results in the creation of an artificial opening for the elimination of waste).

Eating: Person eats with the help of special equipment and/or another person; help includes tube or intravenous feeding, as well as cutting meat, buttering bread, etc. Eating dependency does not include the need for assistance in meal preparation or shopping.

Bathing: Person bathes with the help of special equipment and/or another person.

Dressing: Person dresses with the help of special equipment and/or another person or does not dress.

Mobility: Person walks with the help of special equipment and/or another person or is chair fast or bedfast.

44. Diagnostic Groupings: Number of new admissions (10/1/84 - 9/30/85) in each category.

Report primary diagnosis only, this should represent an unduplicated count. The ICD-9 codes that comprise each category are noted in parentheses following each diagnostic group.

	Number of Enrollees
Mental disorders (290-319)	|__|__|__|__|__|__|
Cancer, Digestive, Blood, Metabolic, and Genitourinary Disorders (140-239, 520-579, 280-289 270-279, 580-629)	|__|__|__|__|__|__|
Circulatory Disorders (390-459).	|__|__|__|__|__|__|
Nervous Disorders (320-389).	|__|__|__|__|__|__|
Musculoskeletal Disorders (710-739)	|__|__|__|__|__|__|
Respiratory Disorders (460-519).	|__|__|__|__|__|__|
Injury (800-959)	|__|__|__|__|__|__|
Other Conditions (1-139, 240-269).	|__|__|__|__|__|__|
No Conditions.	|__|__|__|__|__|__|

The Above Responses Are:
Estimated Data - 1 Actual Data - 2

45. Please estimate the percentage of waiver clients who suffer from:

a) Severe behavioral or mental functioning problems _____%

b) Bowel or bladder incontinence _____%

IX. HEALTH CARE SYSTEM DEVELOPMENTS

46. For each applicable level of care, indicate the total occupancy rate for Medicaid certified beds at waiver approval AND the occupancy rate as of September 30, 1985. Data should reflect all counties in the State. If a level of care is not included in the waiver program, circle NOT APPLICABLE.

LEVEL OF CARE	NOT APPLICABLE	OCCUPANCY RATE AT WAIVER APPROVAL	OCCUPANCY RATE AS OF September 30, 1985
SNF (only)	NA	__ __.__%	__ __.__%
ICF (only)	NA	__ __.__%	__ __.__%
SNF/ICF (swing beds)	NA	__ __.__%	__ __.__%

For programs which are not statewide, please indicate for each level of care the occupancy rate at waiver approval and as of September 30, 1985. Data should reflect only those geographic areas covered by the waiver program. NOTE: If waiver operates statewide as of September 30, 1985, circle NOT APPLICABLE for each level of care.

LEVEL OF CARE	NOT APPLICABLE	OCCUPANCY RATE AT WAIVER APPROVAL	OCCUPANCY RATE AS OF June 30, 1985
SNF (only)	NA	__ __.__%	__ __.__%
ICF (only)	NA	__ __.__%	__ __.__%
SNF/ICF (swing beds)	NA	__ __.__%	__ __.__%

47. In this question, we are attempting to learn whether the waiver program has helped to alleviate the waiting period for individuals seeking institutional care in the waiver program service areas. This excludes persons who are waiting for Medicaid eligibility determination.

	AT TIME OF WAIVER APPROVAL	AS OF SEPTEMBER 30, 1985
Has there been a waiting list of Medicaid recipients in the waiver service areas seeking institutional care?	Yes No	Yes No
IF YES, how long is the average length of wait prior to admission?	<1 month 1-3 months 4-6 months 7-12 months 13-18 months > 18 months	<1 month 1-3 months 4-6 months 7-12 months 13-18 months > 18 months
Have there been hospital back-ups in the waiver service areas due to the unavailability of nursing home beds for Medicaid patients?	Yes No	Yes No
IF YES, how long, on average, do Medicaid patients await placement in a nursing home?	1-5 days 6-10 days 11-15 days 16-30 days 1-2 months >2 months	1-5 days 6-10 days 11-15 days 16-30 days 1-2 months >2 months

48. Since implementation of the waiver program, has a moratorium on new nursing home beds or expansion been established or removed?

Yes - 1 No - 2

IF YES, was the existence of the waiver program a contributing factor to the decision?

Yes - 1 No - 2

IF YES, please indicate: Date moratorium started _____
Date moratorium lifted _____

49. Since implementation of the waiver program, have certification standards been changed to decrease or increase the number of Medicaid nursing home beds?

Increase - 1 Decrease - 2 Unchanged - 3

If a change occurred, was the existence of the waiver program a contributing factor to the decision?

Yes - 1 No - 2

50. Since implementation of the waiver program, have level of care criteria for nursing home admission been made more or less stringent?

SNFs: More Stringent - 1 Less Stringent - 2 Unchanged - 3

ICFs: More Stringent - 1 Less Stringent - 2 Unchanged - 3

If a change occurred, was the existence of the waiver program a contributing factor to the decision?

Yes - 1 No - 2

X. QUALITY ASSURANCE

51. Is each client's care plan subject to review and approval <u>prior</u> to implementing services?

No.....1

Yes, by other person or team within organization/provider entity which developed care plan.....2

Yes, by another organization.....3

IF NO, please skip to 53.

52. If the care plan requires review and approval prior to implementing services, has the review and approval process resulted in excessive delays (ie., potential clients elect to enter nursing homes rather than wait for service initiation)?

No.....1

Yes.....2

Average delay.....|__|__|__| days.

53. Please list the most significant problems which have been found in ensuring the quality of care provided to waiver clients, and any corrective actions which have been taken as a result.

_____

_____

_____

_____

54. The following questions refer to <u>independent</u> review (i.e., independent of the provider and case manager) of certain aspects of the provision of waiver services. For Questions A-D, answer "Yes" or "No" that the specific activity is subject to independent review. If the answer is "Yes" then fill in the remaining boxes, referring to the notes below for the appropriate codes. If the answer is "No," go to the next question.

	Independent Review? Yes/No	IF YES: Organization? (Note 1)	Discipline? (Note 2)	How is Review Conducted? (Note 3)	How Often? (Note 4)	Review Covers? (Note 5)
A. Does the care plan continue to meet client needs?	____	____	____	____	____	____
B. Do clients actually receive the services in the care plan?	____	____	____	____	____	____
C. Is the provision of care directly observed?	____	____	____	N/A	____	____
D. Does Quality Assurance include assessment of client outcomes?	____	____	____	____	____	____

NOTE 1:
<u>Type of Review Organization</u>:

Waiver Program Lead Agency....1
Health Dept.....2
Aging Dept.....3
Social Services.....4
State Medicaid.....5
PSRO/PRO.....6
Other: Provider(specify).....7
Other: Non-provider(specify)..8

NOTE 2:
<u>Review Staff</u>:

Physician.....9
Nurse.....10
Nurse Practitioner.11
Social Worker.....12
Psychologist.....13
Other(Specify).....14

NOTE 3:
<u>Data Sources Used</u>:

Client Record.....1
Face to face client assessment.....2
Central data system.....3

NOTE 4:
<u>How Often</u>:

Annually.....1
Semi-Annually....2
Other (specify)..3

NOTE 5:
<u>Review Covers</u>:

All Clients.....1
Sample.....2

XI. WAIVER MANAGEMENT ISSUES

55. Is your State conducting any of its own evaluation studies of the waiver program?

Yes - 1 No - 2

IF YES, please send copies of any evaluation reports completed to date.

56. Do you have a computerized information system that would allow you to extract the following information on individual clients:

Receipt of other formal and informal long-term care services before and after entering the waiver program?

Yes - 1 No - 2

Waiver program admission and discharge dates?

Yes - 1 No - 2

Limitations in Activities of Daily Living and Instrumental Activities of Daily Living?

Yes - 1 No - 2

Mental Status (eg., MSQ score)?

Yes - 1 No - 2

57. What has been the most problematic aspect of waiver program implementation and operation?

_____

_____

_____

_____

58. How might the HCFA waiver formula, regulations and program administration be improved to permit your State to meet its waiver program objectives?

_____

_____

_____

_____

_____

THANK YOU FOR YOUR COOPERATION IN COMPLETING THIS QUESTIONNAIRE. YOUR RESPONSES ARE A CRITICAL PART OF THE EVALUATION STUDY AND YOUR COOPERATION IS APPRECIATED.

PLEASE RETURN COMPLETED QUESTIONNAIRE IN THE ENCLOSED ENVELOPE.

APPENDIX B

OMB Number 0938-0349
Approved through 12/31/86

Survey of Section 2176 Home and Community-Based Medicaid Waiver Programs

Survey of Waiver Programs for the Developmentally Disabled/Chronically Mentally Ill

Second Annual Survey

January 1986

Please Return to: La Jolla Management Corporation
11426 Rockville Pike, Suite 400
Rockville, Maryland 20852

Attention: Robert Clinkscale
Project Director
(301) 468-0100

This survey is being conducted under HCFA contract number 500-83-0056 with the Office of Research, Health Care Financing Administration, Department of Health and Human Services

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OMB Number 0938-0349
Approved Through 12/31/86

SECOND ANNUAL SURVEY:
SECTION 2176 HOME AND COMMUNITY-BASED MEDICAID WAIVER PROGRAMS:

SURVEY FOR THE DEVELOPMENTALLY DISABLED AND CHRONICALLY MENTALLY ILL

STATE _____ HCFA WAIVER ID# _____

This is the second annual survey of the Section 2176 Home and Community-based Medicaid Waiver Program. The survey is designed to build upon the information gained through last year's survey and provide additional information on the specific operations of waiver programs. We appreciate your time and cooperation.

I. WAIVER ADMINISTRATION

What agency has lead responsibility for the day-to-day operations of the Medicaid Waiver program? Circle one response only.

State MR/DD agency.....1
State Human Services agency (umbrella agency).....2
State Medicaid agency.....3
Other State agency (specify)_____.....4
Other public agency (specify)_____.....5
Other private agency (specify)_____.....6

Lead Agency

Name_____

Address_____

_____

_____

_____

Phone ( )_____

State Medicaid Agency

Name_____

Address_____

_____

_____

_____

Phone ( )_____

PRIMARY CONTACT PERSON: (Person to call with questions about responses to this survey.)

Name: _____

Title: _____

Address: _____

_____

_____

Telephone: ( )_____

II. PROGRAM OVERVIEW

1. What was the effective date of the original waiver?
(If effective was revised, indicate revised date)

Effective Date.....|__|__|__|__|
MO DY YR

2. Has the program been implemented (i.e., have clients received services under the waiver)?

Yes.....1
No.....2

IF YES, on what date did the program first begin serving clients?

Implementation Date.....|__|__|__|__|
MO DY YR

3. TARGET POPULATIONS REPORTED ON THIS SURVEY

Originally, waiver programs were allowed to serve multiple target groups under the same waiver. For research purposes, however, we ask that a separate survey be completed for waivers serving the Aged/Disabled and for waivers serving the Developmentally Disabled and/or Chronically Mentally Ill. This survey is designed for programs serving the developmentally disabled and/or chronically mentally ill. Please indicate which specific target groups are served under this waiver program and reported on this survey.

Chronically mentally ill.....1
Mentally retarded adults.....2
Mentally retarded children.....3
Other developmentally disabled, not mentally retarded:
(Specify)_____.....4
(Specify)_____.....5
(Specify)_____.....6

4. APPROVED WAIVER SERVICES

Below is a list comprising the most common types of waiver services offered under existing waivers. We realize that the 2176 legislation purposely allows States flexibility in what services to offer and how to define those services. For research purposes, however, we need to obtain information within a common set of service categories in order to make comparisons across programs.

DIRECTIONS: Please indicate which services below are approved under your waiver to the target groups specified in the previous question. Based on data from last year's survey, we have grouped some of the less common services into broader categories. If the exact name of your service is not listed, please try to place it in one of the predetermined categories, if possible.

Case Management.....01

Screening and Assessment(if reimbursed separately from Case Management)..02

Habilitation(if yes, circle specific reimbursable activities).....03

- Developmental training within client's residence.....1
- Developmental training outside client's residence (day program).....1
- Therapeutic recreational services.....1
- Meals provided during habilitation programs.....1
- Occupational/speech or physical therapy (if not reimbursed separately).1
- Other (Specify)_____.....1

Respite(if yes, circle specific reimbursable activities).....04

- In-home hourly respite.....1
- In-home overnight respite.....1
- Out-of-home hourly respite.....1
- Out-of-home overnight respite.....1

Residential Services(if yes, circle specific reimbursable activities)....05

- Staffed group home programs (on-site staff).....1
- Supervised apartment programs (on-site staff).....1
- Supervision of non-staffed group home/apartment programs.....1
- Foster care programs.....1
- Financial subsidies to clients' families.....1
- Other (Specify)_____.....1

Personal Care.....06
Home Health Aide.....07
Homemaker.....08
Adult Day Care (if distinct from habilitation).....09
Supplies and Equipment.....10
Emergency Response.....11
Skilled Nursing.....12
Transportation.....13
Occupational/speech/physical therapy (if distinct from habilitation).....14
Housing Modifications.....15
Family training/counseling/support services.....16
Crisis intervention services.....17
Other (Specify)_____....18
Other (Specify)_____....19

5. Please indicate how the following Assessment/Case Management/ Quality Assurance activities are supported under the waiver. In the reimbursement columns, indicate whether the activities are reimbursed as a case management waiver service, as a different waiver service, or whether they are financed through State Medicaid administrative funds or non-Medicaid funds.

		Activity is Funded as....			
		Case Management Waiver Service	Other Waiver Service	Medicaid Admin. Cost	Non-Medicaid Funding
a.	Initial assessment/screening of waiver program applicants	1	2	3	4
b.	Level of care determinations	1	2	3	4
c.	Determination of costs of community care for waiver applicants	1	2	3	4
d.	Final determination of clients' acceptance into the waiver program	1	2	3	4
e.	Initial care plan development	1	2	3	4
f.	Assisting clients in obtaining non-waiver services	1	2	3	4
g.	Coordinating delivery of waiver services	1	2	3	4
h.	Monitoring quality of care provided	1	2	3	4
i.	Review/approval of claims for waiver services (i.e., whether they correspond to services approved in case plan)	1	2	3	4
j.	Periodic level of care redetermination	1	2	3	4
k.	Determination of client cost-sharing liability	1	2	3	4

6. Persons who conduct case management activities <u>reimbursed under the waiver</u> are employees of what types of agencies? Circle all that apply.

State MR/DD agency.....1
State Medicaid agency.....2
Other State agency (specify)_____.....3
Other public agency (specify)_____.....4
Private agency: not a waiver provider.....5
Private agency: waiver provider.....6

III. OTHER WAIVER PROVISIONS

7. Do you presently have a waiver of statewideness?
Circle one response only.

Yes, but services are nonetheless available statewide.....1

Yes, waiver services are restricted to specific geographic areas.....2

No.....3

8. In how many counties are waiver services available?

COUNTIES W/ OPERATIONAL WAIVER PROGRAM	TOTAL COUNTIES IN STATE
___	___

9. Does the State plan to eventually make waiver services available statewide?

Yes.....1
No.....2
Uncertain.....3
Program already Statewide.....4

10. Does your State Medicaid program currently have a Medically Needy program?

Yes.....1
No.....2

IF YES, has eligibility for the waiver program been extended to Medically Needy applicants?

Yes.....1
No.....2

IF NO, has your waiver program exercised the option to extend eligibility to persons who qualify under a Special Income Level (the "300% rule")?

Yes.....1
No.....2

11. Has your waiver program exercised the option to apply institutional deeming rules in determining eligibility for waiver program applicants?

Yes.....1

No.....2

IF YES, please estimate the percentage of waiver clients currently enrolled in the waiver program who would have not been eligible for Medicaid if institutional deeming rules had not been applied.

Percent who would have been ineligible.....|__|__|__|%

12. Has your waiver program exercised the option to deny waiver services to persons for whom the cost of home and community-based care is estimated to exceed the cost of ICF-MR care or other cost cap?

Yes.....1

No.....2

IF YES, what is the specified cost limit in dollars per month and as a percentage of the average monthly Medicaid reimbursement for ICF-MR care?

$ |__|__|__|__|.0|0| per month

|__|__|__| % of average monthly ICF-MR reimbursement.

IF YES, what cost elements are considered under the cost-cap? Circle one response only.

Estimated waiver service costs vs. average monthly Medicaid ICF/MR payment.....1

Estimated total Medicaid costs for waiver client vs. average total Medicaid costs for ICF/MR recipients.....2

Estimated total cost of community care for waiver client including Medicaid and other public costs vs. total public costs for ICF/MR recipients.....3

IV. SCREENING/ASSESSMENT/INTAKE

13. Please indicate which of the following populations are potentially eligible for the waiver. In addition, please indicate whether the population is a special target group (i.e. persons in the group receive priority in being admitted to the waiver). Circle all that apply.

	Eligible for Waiver		Special Target Group	
	Yes	No	Yes	No
Persons receiving care in publicly-operated ICF-MRs	1	2	1	2
Persons receiving care in privately-operated ICF-MRs	1	2	1	2
Persons inappropriately served in non-ICF-MR facilities (e.g. nursing homes, mental hospitals, etc.)	1	2	1	2
Persons previously deinstitutionalized from ICF-MRs and who are at risk for re-institutionalization	1	2	1	2
Persons not previously institutionalized, but who are at risk of institutionalization	1	2	1	2
Persons living at home with their natural families who are at risk of institutionalization	1	2	1	2

14. Are all applicants for ICF-MR admission in the State screened as potential candidates for the waiver program?

Yes.....1
All applicants to public ICF-MRs only.....2
No.....3

15. Please describe briefly how potential waiver program recipients are identified and referred to the waiver program.

16. The Section 2176 legislation and implementing regulations require that waiver program recipients who are developmentally disabled meet ICF-MR level of care criteria. What are the applicable ICF-MR level of care criteria in your State? Describe briefly.

_____

_____

_____

_____

_____

_____

_____

17. As you know, States may apply additional targeting criteria of their own, above and beyond ICF-MR level of care criteria, in determining whether clients are eligible to receive waiver services. Are any additional criteria applied in determining waiver program eligibility in your State?

Yes.....1
No.....2

IF YES, what types of additional targeting criteria are applied in determining eligibility for the waiver? Circle all that apply.

Clients can only be admitted to the waiver from specific facilities.....1

Clients must have actually been referred for admission to an ICF-MR in order to be eligible for the waiver.....1

Additional criteria related to the client's level of disability are applied in determining eligibility for the waiver (e.g. level of retardation, presence of behavioral disorders, etc.).....1

Clients must meet specific age criteria.....1

Criteria related to the client's informal support system are applied in determining eligibility for the waiver (e.g. recent death of a parent, etc.).....1

Other types of targeting criteria (specify)_____

_____.....1

Please describe briefly the specific criteria which are applied:

_____

_____

_____

_____

18. Of waiver program applicants for whom level-of-care assessments are conducted, (not necessarily all persons who are screened as possible waiver recipients) what proportion are determined ineligible for the waiver?

Percent Ineligible	
0 - 5%	1
6 - 10%	2
11 - 25%	3
26 - 50%	4
51 - 75%	5
76 - 90%	6
91 - 100%	7

19. Of those persons who are assessed but not admitted to the waiver program, please estimate the percentage who are not admitted for each of the following reasons. (Example: if 25% of persons turned down for the waiver are not admitted because they do not meet ICF-MR level of care criteria, write "25%" on the corresponding line. Responses should add to 100%.

	Percent
Client did not meet ICF-MR level of care criteria.....	____%
Client did not meet other waiver targeting criteria (beyond level of care criteria).....	____%
Program had reached caseload limit.....	____%
Community-based placement not available for specialized needs of client.....	____%
Client not eligible for Medicaid.....	____%
Estimated cost under waiver exceeded cost of institutional care.....	____%
Service needs already met by other sources.....	____%
Client/family chose institutional care.....	____
Other (Specify)_____.....	____%
Don't know.....	____%
TOTAL	____%

V. ENROLLMENT AND DISENROLLMENT

20. What is the total number of persons ever enrolled in your waiver program as of September 30, 1985? (Waivers that have been renewed or that have been designated as new waivers but which still serve the original client population should count all persons admitted in the original three-year waiver, plus those admitted in the extended waiver.)

Total persons ever enrolled.....|__|__|__|__|__|

Actual data.....1

Estimated data.....2

21. Please indicate the number of unduplicated recipients served by the waiver program in each waiver year. Admission date for each individual is defined as the first date of service. For the current year, please indicate the number of unduplicated recipients served for the year, to date.

Waiver Year	Unduplicated Recipients
Year 1	|__|__|__|__|__|
Year 2	|__|__|__|__|__|
Year 3	|__|__|__|__|__|
Year 4	|__|__|__|__|__|

22. How many new waiver clients were admitted to the program between October 1, 1984 and September 30, 1985?

New enrollees between 10/1/84 and 9/30/85.....|__|__|__|__|__|

23. What was the current active caseload of the waiver program as of September 30, 1985?

Caseload on 9/30/85.....|__|__|__|__|__|__|

Actual data.....1

Estimated data.....2

24. For each year of the waiver, has the actual recipient count based on the number of UNDUPLICATED recipients differed by more than 10% from your original waiver application projections or approved modified projections of waiver recipients? Circle one response for each year.

	Year 1	Year 2	Year 3	Year 4
Recipients served exceeded projections	1	1	1	1
Recipients served fell below projections	2	2	2	2
Recipients served were as projected	3	3	3	3

25. For those who were enrolled in the waiver program on September 30, 1985, how many had been enrolled for each of the following time periods?

NUMBER OF ENROLLEES

Less than six months.....|__|__|__|__|__|
Six months to less than one year.....|__|__|__|__|__|
One year to less than two years.....|__|__|__|__|__|
Two years to less than three years.....|__|__|__|__|__|
Over three years.....|__|__|__|__|__|

Actual data.....1
Estimated data.....2

26. Of those persons who were admitted to the waiver between October 1, 1984 and September 30, 1985, how many were admitted from each of the following entry points? (Point of entry is defined as the client's institutional or residential location at the time of initial assessment and determination of waiver program eligibility). If actual data are not available, please provide estimates.

Entry Point	Number of Admissions
INSTITUTIONAL	
ICF	____
SNF	____
Publicly owned ICF-MR	____
Privately owned ICF-MR	____
State hospital/institution (not Medicaid certified)	____
General hospital	____
Private psychiatric hospital	____
State institution for the mentally ill	____
GROUP RESIDENCE	
Group home	____
Supervised apartment program	____
Foster care home	____
Board and care/rooming house (no services on site)	____
PRIVATE RESIDENCE	
Living alone	____
Living with parent(s) (and possibly others)	____
Living with other relatives (and possibly others)	____
Other living arrangement	____
DON'T KNOW	____

Actual data.....1
Estimated data.....2

27. For waiver recipients who were enrolled in the program on September 30, 1985, please indicate their current place of residence.

	Number of Enrollees
GROUP RESIDENCE	
Group home	|___|___|___|___|___|
Supervised apartment program	|___|___|___|___|___|
Foster care home	|___|___|___|___|___|
Board and care/rooming house (no services on site)	|___|___|___|___|___|
PRIVATE RESIDENCE	
Living alone	|___|___|___|___|___|
Living with parent(s) (and possibly others)	|___|___|___|___|___|
Living with other relatives	|___|___|___|___|___|
Other living arrangement	|___|___|___|___|___|
OTHER (Specify)_____	|___|___|___|___|___|
DON'T KNOW	|___|___|___|___|___|
Total persons enrolled on September 30, 1985	|___|___|___|___|___|

Actual data.....1
Estimated data.....2

28. Of persons who were disenrolled from the waiver program between October 1, 1984 and September 30, 1985, what was the primary reason each person was discharged? If actual data are not available, please provide estimates.

	Number of Recipients
Death	|____|
ICF-MR placement	|____|
Placement in non-Medicaid-certified institution	|____|
Placement in ICF/SNF	|____|
Client transferred to non-waiver service provider	|____|
Did not meet level of care criteria at reassessment	|____|
Lost Medicaid eligibility	|____|
Moved out of service area	|____|
Waiver formula limits forced disenrollment	|____|
Community care costs exceeded cost cap	|____|
Program lost track of client	|____|
Client voluntarily disenrolled but stayed in community	|____|
Other (Specify) _____	|____|
DON'T KNOW	|____|

Total disenrollees between 10/1/84 and 9/30/85 \|____\|

Actual data..... .1
Estimated data.....2

VI. SERVICE UTILIZATION AND EXPENDITURES

29. Please complete the table below for each waivered service delivered during the period 10/1/84 - 9/30/85.

	UTILIZATION AND EXPENDITURE CHARACTERISTICS			
Waiver Services (1)	Total Expenditures (2)	Unduplicated Recipients (3)	Average Cost Per Unit of Service(4)	Provider Reimburse-ment Method (5)

Note:
Column (1). List each waivered service provided.
Column (2). Estimate total expenditures by type of service.
Column (3). Estimate unduplicated recipients by type of service.
Column (4). Estimate average cost per unit of service and identify units; e.g., $32.00/day of habilitation services, $120.00/month of case management, etc.
Column (5). Code "1" for fee-for-service, "2" for capitation arrangement, or "3" other (specify other).

30. How many total unduplicated recipients received waiver services between 10/1/84 and 9/30/85 and what was the total number of days of waiver coverage over this time period? (Note: "total days of waiver coverage" is the sum of enrollment days for all persons covered by the waiver between 10/1/84 and 9/30/85).

Total unduplicated recipients.....|__|__|__|__|__|

Total days of waiver coverage.....|__|__|__|__|__|

31. In implementing the waiver program, has your State encountered difficulties in attracting an adequate supply of providers of waiver services?

Yes.....1

No.....2

Please explain any problems encountered. _____

_____

_____

32. When actual average per capita waiver service costs for waiver clients are compared to projected average per capita costs in each waiver year:

	YEAR 1	YEAR 2	YEAR 3
a. Average per capita costs exceeded projected costs by more than 10%	1	1	1
b. Average per capita costs were less than projected costs by more than 10%	2	2	2
c. Average per capita costs were within 10% of projected per capita costs	3	3	3

If average per capita costs were higher or lower than projected, explain the reasons for the variances below.

_____

_____

_____

_____

_____

VII. SUPPLEMENTARY SERVICES

33. Of persons enrolled in the waiver as of September 30, 1985, please estimate the percentage of recipients who were receiving supplementary services financed by other sources.

	Percent (%) of Recipients
Medicaid home health services not included under the waiver	___
State/Federally-funded vocational training services	___
Services funded through Social Services Block Grant	___
State Supplements to SSI	___
State-funded residential care (excluding SSI/SSP)	___
Federal housing subsidies (e.g., Section 8)	___
State-funded habilitation/developmental training services	___
Federal/State/local special education services	___
Other State-funded services (specify)_____	___
Volunteer services	___
Other (specify)_____	___

VIII. CHARACTERISTICS OF WAIVER PROGRAM POPULATION

For waiver recipients who were enrolled in the program as of September 30, 1985, please provide data on the following characteristics:

34. Age by Sex: Number of males and females in each age group.

	NUMBER OF ENROLLEES	
	Male	Female
Age: 0-14	____	____
15-21	____	____
22-39	____	____
40-64	____	____
65+	____	____
TOTAL	_____	_____

Actual data.....1
Estimated data.....2

35. Type of Disability: Number of enrollees in each category

	NUMBER OF ENROLLEES
Chronically mentally ill	_____
Mental retardation, no multiple diagnosis	_____
Mental retardation, with multiple diagnosis	_____
Other developmental disability, not mentally retarded	_____

Actual data.....1
Estimated data.....2

36. Mentally Retarded Clients Only: Level of retardation. Number of enrollees in each category:

	NUMBER OF ENROLLEES
Mild	|____|
Moderate	|____|
Severe	|____|
Profound	|____|

Actual data.....1
Estimated data.....2

37. For Mentally Retarded Waiver Clients Only: Activities of daily living. Number of enrollees in each category.

	NUMBER OF ENROLLEES	
	YES	NO
Toilet trained	|____|	|____|
Can walk without assistance	|____|	|____|
Can dress without assistance	|____|	|____|
Can communicate verbally	|____|	|____|

Actual data.....1
Estimated data.....2

IX. HEALTH CARE SYSTEM DEVELOPMENTS

38. According to survey data collected by the Center for Residential and Community Services of the University of Minnesota, the distribution of occupied ICF-MR beds, by size of facility, on June 30, 1982, was as shown in the left-hand column below. Please indicate in the right-hand column what the distribution of occupied ICF-MR beds was, by size of facility, on September 30, 1985.

	------Number of Beds------	
Facility Size	6/30/82	09/30/85
1 - 6 Beds		
7 - 15 Beds		
16 - 31 Beds		
32 - 75 Beds		
76 - 150 Beds		
151 - 300 Beds		
301+ Beds		

39. Since implementation of the waiver program, has a moratorium on new ICF-MR beds or facilities been established or removed?

Yes.....1
No.....2

IF YES, was the existence of the waiver program a contributing factor to the decision?

Yes.....1
No.....2

IF YES, please indicate: Date moratorium started ___/___/___ MO DY YR

Date moratorium lifted ___/___/___ MO DY YR

40. What is the total MR/DD budget for non-institutional community-based services (excluding all ICF-MRs, whether or not they are community-based, but including waiver program expenditures) in your State for the present fiscal year? Include funds from both Federal and State sources.

Total community-based services budget.....$_____

For FY_____ which runs from _____ to _____

Please indicate whether budget figure provided above includes...

	Yes	No
State/Federally-funded vocational training funds	1	2
Federal/State/local special education funds	1	2
State Supplementation payments to SSI recipients	1	2
Social Services Block Grant funds	1	2
Other Federal funds (specify)_____	1	2

41. Which agency pays the State share for home and community-based services funded under the waiver?

State MR/DD agency.....1

State Medicaid agency.....2

Both MR/DD and Medicaid agency.....3

Other (Specify)_____.....4

42. Which State agency pays the State share for ICF/MR costs?

State MR/DD agency.....1

State Medicaid agency.....2

Both MR/DD and Medicaid agency.....3

Other (Specify)_____.....4

43. Since the waiver program was implemented, which of the following impacts on the ICF-MR program have occurred in your State and which of these are attributable to the waiver program? Circle all that apply.

	YES, but not due to Waiver	YES, due to Waiver	NO
ICF-MR beds in publicly-operated facilities have been reduced.	1	2	3
Publicly-operated ICF-MR facilities have been closed altogether.	1	2	3
New construction/conversion of public ICF-MR beds has been diverted.	1	2	3
ICF-MR beds in privately-operated facilities have been reduced.	1	2	3
Waiting lists for ICF-MR placement have shortened.	1	2	3
New construction of privately-operated ICF-MRs has been diverted.	1	2	3
Conversion of privately-operated facilities to ICF-MR status has been diverted.	1	2	3
Small-scale ICF-MRs have been decertified under the waiver and converted to non-ICF-MR group home/apartment programs.	1	2	3
Occupancy rates in existing ICF-MR system have declined.	1	2	3
Occupancy rates in existing ICF-MR system have increased.	1	2	3
Other ICF-MR impacts (specify)_____	1	2	3

_____

44. Is your State collecting data which can demonstrate changes in the developmental, behavioral, functional and/or health status of waiver clients over time?

Yes.....1

No.....2

IF YES, please forward any documentation of waiver program impacts on the development of recipients.

X. QUALITY ASSURANCE

Unlike the ICF-MR program, which establishes specific Federal standards for care provided in Medicaid-certified facilities, the waiver program is largely dependent upon quality of care standards established by the States themselves. This section addresses how States have elected to monitor waiver-funded services.

45. Are licensing/certification requirements for providers of waiver services more stringent than requirements for providers of similar services (e.g. residential, habilitation) to non-waiver clients?

Yes, more stringent.....1

No.....2

IF YES, how are licensing/certification requirements for providers of waiver services more stringent?

_____

_____

_____

46. Who prepares the individual plan of care for waiver clients? Circle one response only

Case manager employed by waiver service provider.....1

Interdisciplinary team which includes one or more representatives of provider agency.....2

Interdisciplinary team which includes no representatives of waiver service providers.....3

Case manager employed by intermediary agency which is not a waiver service provider.....4

Case manager or other employee(s) of State Mental Retardation Agency.....5

Case manager or other employee(s) of State Medicaid agency.....6

Other (specify)_____.7

47. Please list the most significant problems which have found in ensuring the quality of care provided to waiver clients, and any corrective actions which have been taken as a result.

_____

_____

_____

_____

_____

48. The following questions refer to quality assurance mechanisms in your waiver program. For Questions A-D, first answer "Yes" or "No." If the answer if "Yes" then fill in the remaining boxes, referring to the notes below for the appropriate codes. If the answer is "No," go on to the next question.

	Yes/No	IF YES: By Whom? (Note 1)	IF YES: How Often? (Note 2)	IF YES: Review Covers? (Note 3)
A. Is the plan of care reviewed by someone not involved in its preparation prior to the implementation of waiver services?	_____	_____	N/A	_____
B. Are providers monitored to determine whether plans of care are being implemented properly?	_____	_____	_____	_____
C. Does monitoring of waiver service providers include the direct observation of clients?	_____	_____	_____	_____
D. Does monitoring include comparing care plan objectives with client outcomes?	_____	_____	_____	_____

NOTE 1: By Whom?

Case manager within provider agency.....1
Case manager in separate private agency.....2
Case manager/employee of State MR/DD agency.....3
Case manager/employee of State Medicaid agency...4
Interdisciplinary team.....5
Other (specify in space below).....6

NOTE 2: How Often?

Annually.....1
Semi-Annually.....2
Other (Specify)...3

NOTE 3: Review Covers?

All Clients.....1
Sample.....2

I. WAIVER MANAGEMENT ISSUES

49. Please indicate the extent of waiver program oversight provided by the State Medicaid Agency.

	Yes	No
a. State Medicaid agency conducts all level of care assessments independently of State MR Agency	1	2
b. State Medicaid agency reviews level of care assessments conducted by State MR Agency	1	2
c. State Medicaid agency reviews all individual plans care prior to implementation of waiver services	1	2
d. State Medicaid agency conducts own licensing/ certification of waiver service providers	1	2
e. State Medicaid agency approves reimbursement rates paid to providers for waiver services	1	2
f. State Medicaid agency approves contracts with waiver service providers	1	2
g. State Medicaid agency reviews claims made for waiver services to ensure compliance with established rates, cost caps, contracts, etc.	1	2
h. State MR Agency pays waiver providers directly and then bills State Medicaid Agency for waiver services	1	2
i. State Medicaid Agency conducts its own audits of waiver service providers	1	2

50. Is your State conducting any of its own evaluation studies of the waiver program?

Yes.....1
No.....2

IF YES, please send copies of any evaluation reports completed to date.

51. Do you have a computerized information system that contains information on the characteristics of individual waiver clients?

Yes.....1
No.....2

52. What has been the most problematic aspect of waiver program implementation and operation?

_____

_____

_____

_____

53. How might the HCFA waiver formula, regulations and program administration be improved to permit your State to meet its waiver program objectives?

_____

_____

_____

_____

_____

THANK YOU FOR YOUR COOPERATION IN COMPLETING THIS QUESTIONNAIRE. YOUR RESPONSES ARE A CRITICAL PART OF THE EVALUATION STUDY AND YOUR COOPERATION IS APPRECIATED.

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